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#### **ABSTRACT**

This monograph presents an evaluative description of the Alaska Youth Initiative (AYI), a community-based interagency program serving children and adolescents with severe emotional and behavioral disorders. Principles of the program include a no reject policy and a "wraparound" service delivery approach. The monograph offers information on both process and outcome in descriptions of the lives of 10 children and adolescents before, during, and after their experience with AYI. The first section (by John D. Burchard and Sara N. Burchard) consists of seven chapters which explain how the case studies were conducted; summarize results and implications; and present the case histories including three cases of schizophrenia, a native Alaskan youth (highlighting the challenge of cultural competence), a gay youth, two youths labeled borderline personality, and three individuals with conduct disorder. Section II (by Robert Sewell and John VanDenBerg) details the purposes and operation of AYI. This includes a mission statement, identification of principal features of individualized care, the process from referral to acceptance, the process from acceptance to service plan, and the process from service provision to discharge. (Contains 58 references.) (DB)

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# ONE KID AT A TIME

# **Evaluative Case Studies and Description** of the

## Alaska Youth Initiative Demonstration Project

John D. Burchard, Ph.D. Sara N. Burchard, Ph.D.

and

Robert Sewell, Ph.D. John VanDenBerg, Ph.D.

August 1993

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# ONE KID AT A TIME

## Evaluative Case Studies and Description

#### of the

## Alaska Youth Initiative Demonstration Project

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## **Foreword**

Imagine the most troubled youngster from your state who has spent the last 2 years in an extremely restrictive out-of-state residential placement. Then, imagine inviting him or her into your home. You are then asked to give him or her unconditional care: to stand by this youth regardless of how difficult he or she is to live with, how badly you are treated, or how much destruction he or she reaps upon your family, your community, and himself or herself.

You are also asked to work together with this youth, his or her family, and a group of community helpers to find, through experimentation, the combination of supportive and therapeutic interventions that will help this young person function at a higher level. And, if it works, you must be prepared to change the plan tomorrow, if need be. If it doesn't work, you must be prepared to change the plan today. You are asked to go after the child when he or she runs away, which will happen. You are asked to invite this young person back from jail after he or she has stolen and wrecked your car. You are asked to live with this youngster through periods of delusions, hallucinations, substance abuse, suicidal behavior, and/or sexual promiscuity.

Imagine your surprise when, after you have done this for 6 months, the youth begins to look and act like most other children his or her age. While the child still has significant emotional problems, his or her behavior has settled down to the point that the emotional problems become workable within the community, often within the youngster's own family and school. This has been the experience of the Alaska Youth Initiative (AYI) where the "you" is the child, the family, and a collection of other involved community individuals, some of whom are human service professionals. The reality is that this task is extremely difficult and requires a high degree of risk taking by the individuals involved.

Traditionally, our service systems have not been inclined to take such risks. Rather, they have found it easier to place children in highly restrictive residential and psychiatric hospital settings where "they" are safe. However, it is not always clear who "they" are. While it may be true that out-of-control behavior is easier to control in a restrictive setting, children in these settings still run away, are promiscuous, engage in self-destructive behavior, and have access to abusive substances. Additionally, there is little that happens in these settings that makes children safer within their home communities when they are ultimately returned. Often it appears as if the "they" who become safer are the professionals and other helpers in the community service system. When a child is in a restrictive placement the involved individuals, including the family, can sleep comfortably knowing that the child will be fed and "safely" kept. For the worker, there is little personal risk or discomfort.



It is very difficult to make the decision to keep these same extremely troubled young people in their communities. For this decision means to struggle every day with the child's problems and to wonder each day and night if you have made the right decision. Each day you wonder if you can justify your decisions when someone asks, "Why did you do that?" or "Why did you allow that to happen?" When it works, the choice to serve the child in the community is right. Even when it doesn't work very well, the choice is still right. The AYI approach allows children and their families to live the most normalized lives possible: lives which are controlled by their strengths rather than limited by their problems. Even if an AYI child must ultimately be institutionalized, the child, family, and community have had an equal opportunity to learn the power of an unconditional approach and a positive, strength-based attitude. It is within this context that AYI has pushed communities to resist restrictive placements and to struggle with meeting the needs of their young people at home.

AYI has been a most important national demonstration. In 1984, the State of Alaska received a grant from the first round of funding of the National Institute of Mental Health's (NIMH) Child and Adolescent Service System Program (CASSP). Through this grant, the state intended to move toward the national CASSP goals which included creating a new interagency approach to the care of children and adolescents with severe emotional disturbance. Unlike most states that focused on the development of state and local interagency service coordinating mechanisms, Alaska took a much more direct service level approach. The leaders of the Alaska CASSP realized that one way to facilitate interagency coordination and cooperation was to offer Alaskan agencies a way to save money by bringing back to the state those children and adolescents who had been sent to expensive, restrictive, out-of-state residential treatment centers and psychiatric hospitals. However, in order to do this, the agencies had to work collaboratively and to pool the funds that they were currently using to support institutional placements.

The approach that was developed and was ultimately to become AYI was borrowed from Kaleidoscope, an alternative youth program in Chicago. Kaleidoscope grew out of the alternative service movement for youth that began in the late 1960s. The underlying principle of this program was that of unconditional care. This concept is best portrayed through the tenet of "no reject, no eject." From a functional point of view, this means that the program accepts any child who is referred regardless of the types of behaviors that the child has displayed in the past, and that child will not be punitively discharged from the program regardless of what kind of behaviors the child displays while in the program. This type of approach requires a new service delivery philosophy in which service providers are seen as being there to meet a child's changing needs. When the child has problems, the provider must look for a different, more effective intervention approach rather than placing blame on the child and family. In contradistinction, in our current system, providers offer a limited range of service and,



if a child and family do not respond well to the intervention program, the blame is placed on that child and family who are then referred to another service provider for a more restrictive service.

As can be seen in the document that follows, Kaleidoscope and AYI use an extremely flexible service model which has been conceptualized as taking service and wrapping it around the child and family. These "wraparound services" require an assessment and service delivery approach that looks across all areas of a child's and family's needs and works with those individuals to provide the necessary supports and specific therapeutic interventions. Further, in order to be flexible enough to provide the wide range of services that this approach often requires, the funding of the services needs to be equally flexible.

AYI created an experiment in which the wraparound service philosophy was applied to an interagency state program for children and adolescents with severe emotional disturbance. This new model of service delivery provided the national CASSP movement with an intervention framework through which to actualize the principles of the CASSP System of Care as described by Stroul and Friedman (1986). As the leaders of the CASSP movement across the nation struggled with how to take our current system of component-based services and construct a flexible integrated system out of them, AYI offered a practical alternative to the traditional service delivery approach. Within the individualized approach, the traditional service components would become pieces that would fit into the individual service mosaic constructed to meet the full range of needs of each child and his or her family.

Just as AYI has been important to the development of national service systems for children and adolescents with severe emotional disturbance, this current study by John and Sara Burchard is an important step in broadening the general acceptance of AYI and individualized wraparound services. This study is an evaluative description of AYI and of the service delivery approach it has espoused. It offers information on both process and outcome that can be used to support this approach by describing in detail the lives of 10 children and adolescents before, during, and after their experience within AYI. The study describes the struggle between the traditional and the new wraparound approaches. It gives each reader the chance to understand that offering this kind of service means both having to live with daily uncertainty and having to accept the shift of responsibility from professionals to the youth and family. In doing so, the study takes the same risks as the AYI service teams it describes. It assumes that the reader will look past what often appears to be a chaotic beginning of an AYI intervention; will struggle with discovering, along with the teams, the proper approach-of-the-day for each child; and will judge whether or not the final outcome for each youngster and family is better than living many years in an institution half a continent away from home.



The study takes further risks. Unlike most evaluative and descriptive studies, this work takes an in depth look at the dark side of each case presented. How many of us ask the question, "What might have made it work better?" and then answer it by looking at ourselves as a major barrier? How many of us would take the chance to describe in detail how we had to muddle through new intervention territory with no guideposts and much opportunity to take the wrong trail? Rather than just reporting the components of success, this study discusses the process of making decisions, some right and some very wrong. This non-selective, descriptive approach reflects the principles of unconditional wraparound care and is a startling demonstration of the important message that when care decisions go wrong, we cannot give up on children and pass them on to others. Rather, we must learn not to blame the children and their families for the problems, but to retrace our steps and try another approach.

As I read these case histories, it was very easy to sit back and ask, "Would I have done it that way?" Probably not. I wasn't there. I have the luxury of distance and aftersight. Most importantly, I probably would have been unwilling to take the risk involved. While the study may raise some questions as to the adequacy or appropriateness of some of the specific interventions, it must be remembered that the technique of wraparound services is experimental and that AYI was, at the time of the study, still in its early developmental phase. On the other hand, in the true process of wraparound service delivery, each individual case will always have an experimental and developmental phase. As intervention teams struggle to find the most adequate and appropriate services for individual children and families, they may try approaches that turn out to be inadequate and inappropriate. With the AYI model, each of these failures offers more information to the team and helps them to define a service approach that is more adequate and appropriate.

Has anybody been more successful in finding adequate and appropriate services for these children? The reader may judge for himself or herself. Most of the AYI children suffered through years of failed response to services which traditionally had been accepted as adequate and appropriate. The fact that we feel comfortable with these "tried and true" service options does not necessarily mean they are adequate or appropriate services for any one individual child and family; and many times, they are not. Is it more acceptable for a child to fail in a traditional service intervention than in a nontraditional one? The test is not in the response to an individual service; rather, the test is in what the service system learns from that response. Our traditional approach is to bounce children around from one unsuccessful traditional program to another without learning much from the last experience that can be useful in planning the next. With the AYI approach, the child, along with a whole team, moves from one intervention to the next, each time learning more about what is likely to work. Often what works is very nontraditional, and, on occasion, maybe even bizarre.



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Another issue that this study raises is the place which families have in AYI care. One of the major tenets of AYI and the wraparound models is the primacy of the role of the family and home. The least restrictive living arrangement is in a family's home. Parents are expected to be important members of the service team assembled to develop and monitor the care of the child. Yet, in studying the cases presented, it is clear that many of these children are not living in their homes and that parents are often not major players in the child's care. Again, the reader should ask questions as the study is read. One of these is, "Where were the families when AYI entered the picture?" Many of these cases represent situations in which the service system had lost touch with parents many years before. There comes a point over time in these situations when reunification of a child with his or her family is not a practical or desirable option. In those situations, AYI has held to the principle that the most home-like setting possible is sought.

Another family-related question that follows is, "Where was the family after AYI became involved?" The reader should examine the degree to which parental involvement increased. This includes the growing role of parents in the lives of children, even when it is realized that some parents may never be able to be the primary caretaker for their children. The experience of AYI that is represented in this study demonstrates the growing role of parents in the lives of their children as encouraged by the treatment teams.

Everyone who dreams of a world where children and their families can obtain an array of services that meets the full range of their needs will learn from this study some lessons that will bring them a number of steps closer to that dream. As we read and learn, we need to thank the many individuals who took the risks inherent in the struggle to develop these new approaches. This includes the children, their families, the teams who worked together, and, most of all, those tireless individuals who accepted the burden of unconditional care for individual children. We must thank Karl Dennis and Mel Breed of Kaleidoscope, as well as Barbara Minton, John VanDenBerg, and Robert Sewell of AYI, and the State of Alaska CASSP for daring to propose and develop the wraparound service philosophy and the Alaska Youth Initiative. And, finally, we must applaud John and Sara Burchard for this exciting descriptive study of AYI so that we can all learn the important lessons that it offers us.

Ira S. Lourie, M.D. Human Service Collaborative Washington, DC



## Preface

This monograph presents a qualitative case study evaluation of 10 youth with severe behavioral and emotional problems who received services under the auspices of the Alaska Youth Initiative Demonstration Project between 1986 and 1991. This 5-year demonstration project, herein referred to as AYI, was designed to provide intensive, individualized, community-based "wraparound" services to the most challenging Alaska youth, ones for whom all available alternatives to long-term residential treatment (usually out of state) had failed. This monograph also includes a description of the system and procedures that AYI personnel developed in order to serve these youth in community settings.

The case studies that follow were conducted by John and Sara Burchard, psychologists from the University of Vermont, as an independent evaluation for AYI. Section I of this monograph presents the case studies. The first chapter describes how and why this research was conducted. The second chapter contains a review of the case findings and a discussion of the common themes that emerge. This chapter focuses on those aspects of the AYI service delivery approach that seemed to be most effective, based on the information that was accumulated across all the cases; it also includes some of the authors' observations on how the delivery of individualized, wraparound services might be improved. The remaining five chapters in Section I provide detailed descriptions of the 10 cases with multiaxial timelines that highlight, on one visual field, the occurrence of significant behaviors, events, services, and service costs before and after each youth entered AYI.

Cases involving common psychiatric diagnoses have been grouped into single chapters. There are chapters presenting multiple cases of youth with the diagnosis of schizophrenia, borderline personality, and conduct disorder. The grouping of cases by diagnosis is done to emphasize the individualization of AYI services to youth despite their perceived similarity with regard to the type of emotional disturbance they experienced. Separate chapters focus on two cases that illustrate special issues: one on the provision of services to a youth who is gay and the other the challenge of providing services that are culturally competent to a Native Alaskan youth.

Section II of the monograph provides information on the development and implementation of the Alaska Youth Initiative demonstration project as presented by Robert Sewell and John VanDenBerg. John VanDenBerg, Director of AYI throughout the demonstration project, was the driving force behind the development of the individualized, community-based services approach. Robert Sewell was the Director of Residential Services during the early stages of AYI and a Regional Coordinator from



1988 to 1990; he spent the last year of the project as the Coordinator for Individualized Services. This section describes the service mandate, the evolution of the individualized, community-based service approach, and the procedures that were eventually operationalized in order to serve a large proportion of the most challenging youth in Alaska.

It should be noted that within this monograph precautions have been taken to protect the confidentially of the youth and their families. Some factual demographic characteristics of each case are changed to minimize recognition and identification. The authors believe that these changes do not distort the description or interpretation of the interactions of the youth with the service delivery system.

Finally, the authors wish to express their appreciation to all the youth, parents, advocates, service providers, and administrators who took part in the development, implementation, and evaluation of the AYI demonstration project. The primary message in this monograph is that it is possible to improve a service delivery system for extremely challenging youth. As evidenced by AYI, creativity, enthusiasm, persistence, and the cooperation of hundreds of stakeholders are important factors in making it happen.

# **SECTION I**

Evaluative Case Studies
From the Alaska Youth Initiative

John D. Burchard, Ph.D.

Sara N. Burchard, Ph.D.



## CHAPTER 1

## How the Case Studies Were Conducted

#### The Alaska Youth Initiative

In 1985, Alaska received one of the first 10 state grants from the National Institute of Mental Health's Child and Adolescent Service System Program (CASSP). The purpose of these 5-year demonstration grants was to improve services to children with severe emotional disturbance and their families. In Alaska's case, the focus of the CASSP funds was to discontinue the use of out-of-state placements.

The effort to provide an in-state alternative to out-of-state placements became known as the Alaska Youth Initiative (AYI). The service strategy that AYI developed under the leadership of its director, John VanDenBerg, is now referred to as individualized or "wraparound" services. The development of the wraparound model relied heavily on the pioneer work of Karl Dennis and his staff at Kaleidoscope, an alternative youth program in Illinois, together with considerable on-the-job training.

Section I of this monograph presents the results of the qualitative case study evaluation of 10 youth served by AYI during the 5-year demonstration period. Section II describes in detail the evolution and implementation of the AYI service delivery model. Seven basic characteristics of the AYI individualized, wraparound services are outlined below in order to provide an orientation to the philosophical base for the services that the 10 youth received.

Individualized, wraparound services consist of an array of services that are developed and coordinated by an interdisciplinary services team. These services are community based, culturally relevant, unconditional, and are individually and positively focused on three or more life-domain areas of the child and family. These basic characteristics are described below.

• Interdisciplinary services team is a youth's service planning team which commonly includes: (a) the biological parent(s), if they have legal rights to the youth or the adoptive parent, if the youth has been adopted; (b) the youth, if it is felt the youth can contribute to and benefit from the process; (c) the case worker or probation officer, if the youth is in the custody of the



state or county; (d) a caretaker, if the youth is not living at home; (e) an education representative (lead teacher, vocational counselor, or school psychologist, depending on who is the most involved with the youth); (f) a therapist or counselor, if the youth is receiving mental health services; (g) a case manager or service coordinator; (h) an advocate for the youth and/or parents; (i) any other person in the youth or parent's life who may be instrumental in the delivery of effective services (a neighbor, a physician, a relative, or a friend).

- Community-based means receiving services in the community or rural area where the youth's family and/or relatives reside. Restrictive institutional and group care should be utilized for brief stabilization only.
- Culturally relevant means having services administered by persons of the same culture as the youth wherever possible and, at the very least, having services provided by persons who are sensitive and respectful of the culture of the child and family.
- Unconditional indicates that the service team agrees to never deny services because of the severity of the youth's problem behavior, to change services as the needs of the youth and family change, and to never reject the youth and family from services.
- Individualized signifies that services are based on the specific needs of the child and family and not on a particular categorical label and intervention model. Individualized services may be both traditional (therapy, foster care, medication) and non-traditional (hiring a special friend, arranging for a staff member to live with a family, fixing a car or washing machine, providing the family with a telephone). Traditional services are used only when they can be tailored to the specific needs of the child and family.
- Positively focused means that the service plan incorporates the positive aspects of the youth, family, and community.
- Life domain areas are areas of basic human needs that almost everyone experiences. These areas are: familial (biological or surrogate family); residential (a place to live); social (friends and contact with other people); educational and/or vocational; medical; psychological/emotional; legal (especially for youth with juvenile justice needs); safety (the need to be safe). Other specific life domain areas also exist such as cultural and ethnic needs, as well as needs related to sexual preference.

#### Case Study Evaluation

This evaluation is not a summative evaluation of AYI nor is it a comparative evaluation of individualized services with respect to any other specific service modalities. Rather, it is a qualitative analysis of 10 rather extraordinary cases based on data obtained from the persons who provided the services, from the parents and youth who received the services, and from agency case files. The cases were extraordinary from several perspectives. They were extraordinary from the perspective of the length of time during which the behaviors of the youth had constituted a serious threat to themselves and to their communities, the lengths to which the service sector had gone to serve them, and the number and variety of interventions that had failed in the service sector's efforts to contain and serve these youth. Prior to their acceptance into AYI, most of these youth had spent considerable time in many restrictive residential placements both inside and outside Alaska.

There were other rather extraordinary aspects and challenges presented by these cases. Some cases were extraordinary from the perspective of the difficulties inherent in serving youth from a non-Western, Native Alaskan cultural tradition. Other cases were extraordinary from the perspective of geography; many of the youth lived in very isolated and remote regions of Alaska which were only accessible by boat or plane.

#### Case Selection

The cases for this study were selected during the second quarter of 1990, the beginning of the 5th year of the AYI demonstration project. All AYI cases which had received at least 6 months of AYI service at the time of selection, whether the youth had been discharged or was still receiving services, were included as potential cases for study. There was a total of 81 such cases. The state AYI director and the three regional AYI coordinators then gave independent qualitative ratings to each case (each case was thus rated by two people) based upon two criteria: the successfulness of the case and its instructiveness. The "successfulness" scale was defined as: information/unknown outcome, 1 = poor outcome, 2 = mixed outcome, and 3 = successful outcome. The "instructiveness" scale was bracketed by 1 = not instructive and 3 = highly instructive. The independent ratings from each of the two raters on each criterion were combined, allowing scores to range from 0 to 6 for successfulness and 2 to 6 for instructiveness.

Based upon the successfulness ratings, 54 (67%) of the 81 rated cases tied with total scores of 6. Twelve cases were rated as having mixed outcomes, 13 had poor outcomes and 2 had unknown outcomes at the time of the rating. The 54 successful cases were then rank ordered by their combined instructiveness scores. Five cases tied for the

highest rank, receiving the highest possible rating of 12 and were included in the study sample. Ten additional cases tied for the second rank, receiving the next highest possible score of 11. Five cases were then selected from those 10 cases to provide case representation across age, ethnicity, diversity of geography and community of tie, diversity of presenting problems or psychiatric diagnosis, and current residence in the state. The remaining 44 cases which received lower instructiveness scores were those that raters viewed as easier to resolve, less challenging, or involving more commonly encountered situations. Two were eliminated because the youth were residing out of state at the time of the evaluation.

#### Setting

The evaluation was conducted between July 1 and August 28, 1990, in the state of Alaska. It was summer in Alaska and, as such, it was daylight almost 24 hours a day. So much daylight removes many of the usual time constraints that the diurnal cycle imposes upon activities, including work and travel related to interviewing. Having to complete some task or interview, or to find some remote residence before dark, was never a constraint during this evaluation, nor was inclement weather (with one exception) a hinderance to performance.

Alaska, which is twice as large as the state of Texas, extends from the 51st parallel in the west (which includes the Aleutian Islands, close to the Kamchatka Peninsula in what was the USSR) to the rain forests and islands of the Pacific Northwest in the east which snuggle up to impassable mountain ranges clothed in the world's largest ice fields, effectively isolating this region from adjacent Canada, a few miles away. The northern border is the 72nd parallel found in the tundra and ice of the Arctic Circle. Midway within these extremes lies Central Alaska which includes, in addition to several mountain ranges and a long coastline, the populated, settled regions of the Kenai Peninsula, Anchorage, and the interior area surrounding Fairbanks. These areas represent the more recent settlement in Alaska of the dominant, Western culture. These also are the only regions within the state which are connected to each other by roads. North and west of central Alaska are subarctic regions, called Bush Alaska, where Native Alaskans (Aleuts, Yupik and Iniupiak Eskimos, and Athabaskan Indians) live in subsistence villages which usually can only be reached by plane or by boat from the ocean (almost as readily from Japan or Russia as from other parts of Alaska).

The 10 cases selected for intensive study were drawn from a broad range of locations, cultures, and environments throughout Alaska. To reach the youth, their families, service sites, and providers entailed considerable travel during the 2 months of the study, involving relatively little ground transport as only the Anchorage, Kenai, and Fairbanks regions are linked by roads. Sites within the Alaskan Southeast Region (the



Pacific Northwest rain forest region) are accessible by a combination of air and water (ferry) transport, and the bush villages of the subarctic regions are accessible by air combined with small water craft in the summer. In order to reach major informants, it was necessary to use public air transport, chartered bush plane, ferries, car, and outboard-powered rowboats. AYI youth were being served in cities, towns, and in a Native Alaskan bush village near the Bering Sea. The latter produced the only impediment to travel. A heavy storm precluded all transport by bush plane and should have precluded outboard motor river transport. (It is not clear whether the steadfast and implacable village fisherman who provided transport was fearless or saving face during this nearly disastrous river trip.)

#### The Youth

The 10 youth included 5 females and 5 males. They had first encountered state services between the ages of 2 and 16, had entered AYI between the ages of 8 and 18, and were between the ages of 9 and 21 at the time of the evaluation. Eight youth were age 15 or over at the time of their entry into AYI, which usually occurred after many years of fruitless efforts to provide effective services for them (see multiaxial timelines within each case study). Three youth were Native Alaskans from three different, widely dispersed ethnic groups. One was of Hispanic ethnicity, and six were Euro-Americans from the dominant culture. At the time of the evaluation, three females had been in AYI over 3 years, entering during its first year, two youth had been with AYI for over 2 years, four youth for between 1 and 2 years, and one youth had been in AYI for 9 months.

Five youth, 3 males and 2 females between the ages of 17½ and 21, had been discharged at the time of the evaluation; five, ages 10 to 19, were still active AYI cases. The list of psychiatric diagnoses for these youth at the time they were admitted to AYI included: borderline personality, conduct disorder, depression, substance abuse, attention deficit hyperactive disorder, possible multiple personality, and schizophrenia. Behaviorally, the cases presented two general profiles. Seven youth were presenting markedly externalizing profiles which included highly aggressive, assaultive, self-abusive, suicidal, and sexually promiscuous behaviors. Several of these seven youth were serious substance abusers. The remaining three youth displayed thought disorders more characteristic of adolescent onset schizophrenia.

With respect to prior familial history, seven youth could be considered "social casualties," coming from backgrounds with severe childhood trauma, including sexual and physical abuse, neglect, and/or family violence. Three youth came from culturally normative, two-parent family settings. It is important to note, however, that the existence or nonexistence of early childhood trauma did not correspond in a one-to-one



fashion with the resulting youth behavioral profile, be it externalizing or schizophrenic. One female with an externalizing profile came from a normative family environment with two biological parents, while one male with schizophrenia came from an environment which included suspected family violence and substance abuse.

#### The Parents

The involvement of the natural and adoptive parents in the delivery of AYI services to the 10 youth varied considerably. In only three cases were parents active participants on the Core Services Team (CST). In an additional four cases, involvement varied from very infrequent to ongoing communication with the service team and youth. In one case, there was little contact because of an intense rejection of the parents by the youth. In another case, the parent lived a considerable distance from the youth and AYI staff felt that additional contact would be too disruptive to the youth. In a third, the parent was a team member until he went to jail. In the fourth case, the youth was over 18. Nonetheless, he and his Core Services Team maintained ongoing contact with his parents, although they were not active team members. In the remaining three cases, the natural parents expressed little or no interest in maintaining contact with the youth.

For the most part, the low rate of active parental involvement in these 10 cases appeared to be a function of the AYI selection process which only accepted youth who were being returned from an out-of-state placement or for whom the AYI program was a last resort to being placed out-of-state. For many of these youth, the natural family ties had long since been broken or abandoned. For example, in five of these cases, the youth had been removed from their parents for reasons of abuse and/or neglect prior to their participation in AYI, and all efforts to reunite them with their natural families had failed.

#### **Procedure**

Initial interviews were scheduled with the local AYI case coordinators. With their assistance, case records were obtained and reviewed, individuals who played a major role in the lives and services of each youth were identified, and interviews were scheduled with as many as could be contacted and reached within the time constraints of the 2-month study period. Interviews also were scheduled with the key members of the Core Services Team and other primary persons in the case, including current and former direct service providers, educators who had worked with the youth, the child welfare worker associated with the case, the probation officer if one was involved, the mental health worker or psychologist, the youth's parents or grandparents, and the youth himself or herself. Permission was obtained from parents and youth for their

participation in the review and they were given an honorarium for their time: \$20 to parents, \$15 to each youth.

Youth, parent, and provider interviews were conducted separately and in private. The interviews were arranged and conducted at the convenience of the interviewees. Most family members were interviewed in their homes; one was in a small Native Alaskan village in the bush which could only be reached in the summer by plane or by a boat ride up a large, winding river. Another family was interviewed in a Native Alaskan village in the rain forest reached by bush plane or ferry, and another in a converted bus located down a maze of dirt roads in a forest. Two parents specified public settings for their interviews. The youth were interviewed in their current residences or, in one case, at a summer camp. Service providers were often interviewed in their work settings: schools, supervised apartments, group homes, institutions, community mental health centers, correctional facility. Conducting interviews in these settings provided the evaluators with the opportunity to obtain additional information about the environmental settings and service programs with which the youth were involved.

This study was conducted in its entirety by Drs. John and Sara Burchard, professional psychologists and trained, experienced interviewers. Both interviewers were present and participated in over 80% of the interviews for reliability purposes. Interviews with family members and service providers were usually 2 to 3 hours in length. Youth interviews were between 45 minutes and 1½ hours in length.

#### Respondents

During the 10-week study period, 72 face-to-face structured personal interviews were completed. Between five and seven individuals were interviewed regarding each case, including the youth and a parent whenever possible. Since five of the cases had been closed, some youth were not readily available. In fact, one was in the Lower 48 on his own with his whereabouts unknown when his case was selected for review. He, however, returned to Alaska and asked to see the reviewers in mid-summer.

Interviews were obtained with 9 of the 10 youth whose cases had been selected. One youth had moved several times and, when her residence was located at the end of the 10-week study period, she had just left for several days to visit a friend who was incarcerated in a penal institution. Therefore, she was not available for interview. Natural parents were interviewed in the five cases where there was at least minimal involvement with the youth. In the remaining five cases, the only interviews with a natural family member included one interview with a grandmother. All the remaining interviews were with adoptive parents, foster parents, AYI staff, educators, professionals in mental health, social services, and corrections, and advocates of the youth.



#### Structured Interviews

The content of the interviews varied depending upon the role of the interviewee in the case. The three major categories of interview were: parent interview, youth interview, and service provider interview. The interviews given the parent and service providers were similar in that they asked the respondent to provide background with respect to the major events that took place in the youth's life, the youth's behavior, services received, and outcomes (i.e., successes, accomplishments, barriers). They were also asked about ways to improve the service and their views on the youth's current and future needs. In addition, respondents were asked to make a specific evaluation of AYI: what its role was, what its objectives were, how it worked, how well it worked, what its major accomplishments were, what they attributed these accomplishments to, what the major barriers were, and what the respondent would do differently if he or she were to do it again.

If the respondent was a team member, she or he was asked to evaluate core team functioning with regard to team coordination, participation, and feedback. Parents were asked to rate each identified service on a 4-point scale of helpfulness (very helpful, helpful, not helpful, or harmful) and were asked to describe in what ways the service was helpful or not helpful, and in what ways it could be improved. They were also asked to describe their involvement with that service and how satisfactory that involvement had been.

In addition, parents and the most recent residential provider were asked to complete the Achenbach Child Behavior Checklist (Achenbach & Edelbrock, 1986) which asked for retrospective reports on how the youth was behaving when they first required formal intervention (parents) or from the time when they first came into contact with the youth (providers). The Checklist also asked their report on the youth's current functioning.

In the youth interview, youth were asked to evaluate each service in terms of its helpfulness and to indicate how it could have been improved. They were also asked about their involvement with the planning or implementing of that service and how satisfactory that had been. They did a 4-point rating providing rationales for their responses, as did their parents. They also were asked to describe what services or supports they felt they would need in the future.



#### Analysis

Information obtained from the interviews and record review for each case was compiled. Information about factual events was checked across multiple informants for accuracy, and discrepancies were checked against permanent records. A multiaxial timeline was then constructed that reflected: (a) the onset of the youth's major problem behaviors, (b) major events in the youth's life, (c) family services, (d) educational services, (e) residential services, and (f) costs of services. In general, the boxes on each timeline designate when services started and stopped, the height of the boxes approximates the restrictiveness of the service, and the term "costs per day" pertains to residential costs before AYI and costs of the individualized services during AYI.

Interview data and information obtained from the case files were examined for common themes and convergence of attributions in order to identify: (a) what constituted successful case outcomes, (b) what factors were associated with or identified as promoting the successful outcomes, (c) what constituted barriers to effective services. Each case was then written in narrative form with the following organizational structure:

- Background
- Alaska Youth Initiative: Services and Outcomes
- Evaluation: What Made It Work?
- Barriers To More Effective Services
- Conclusions

The information for these cases was taken from various sources which are identified in each chapter. In order to protect the identity of respondents and participants in this evaluation, some case information was aftered in the narrative when that information was not germane to the etiology of the youth's needs, services, or outcomes. Such changes entailed gender, specific familial relationships, family constellation, and community of tie or service location.



### CHAPTER 2

## Results and Implications

This chapter integrates and summarizes the findings of the 10 cases that were the focus of this study. A detailed description of each case is presented in chapters 3 through 7. The case studies follow the chapter on results and implications to flesh out and make specific the overall findings.

The primary purpose of the overall study was to identify those elements of the cases that contributed to youth's improvement as well as to identify barriers to the provision of individualized services. This chapter includes an analysis of what constitutes "success" for youth with severely emotionally disturbed behavior from the perspective of their providers and recommendations for service improvement. Study findings are framed as answers to the following six questions:

- 1. Who were the youth selected for review, and how emotionally disturbed were they?
- 2. To what extent was AYI an alternative to long-term residential care?
- 3. What was the success of AYI?
- 4. How likely is it that the youths would have improved without AYI?
- 5. What AYI services and policies were most commonly associated with successful outcomes?
- 6. What might improve the AYI service or an individualized, wraparound delivery system?

# Who were the youth selected for review, and how emotionally disturbed were they?

Ten youth (five male and five female) were evaluated for AYI. At the time of this evaluation, eight were between the ages of 17 and 21, one was 9, and one was 13. Prior to receiving AYI services, these 10 youth were all experiencing severe emotional and



behavioral problems that had resulted in diagnostic classifications which included conduct disorder, attention-deficit disorder, schizophrenia, affective disorder, and/or borderline personality.

All but one youth (Gregory) had an extensive history of emotional and behavioral problems which included varying combinations of aggressive, assaultive (of themselves and others), sexually promiscuous, and unmanageable acting-out behavior. Gregory's problem behavior was severe, but was restricted to acute episodes of a thought disorder. All but two youth (Gregory and Ned) had failed most available treatment options in Alaska, including varying degrees of family counseling, special education services, foster placements, group home placements, drug rehabilitation, psychiatric evaluation and treatment, intensive treatment units, and residential psychiatric and correctional placements. Gregory was never removed from home, and Ned entered AYI just prior to being sent out of state. The eight who traveled throughout the service delivery system most were known as "first-name kids" (e.g., they had been involved in so many unsuccessful service efforts throughout Alaska that many service providers in the state knew them by their first names).

At the time of entry to AYI, 7 of these 10 youth were already institutionalized (Mary, Tony, Gretchen, Alexis, Carol, Jim, and Gloria) and 2 were being considered for imminent institutionalization (Jill and Ned). The family of the remaining youth (Gregory) was determined to find community, home-based care for their family member and was able to access AYI services shortly after the onset of his schizophrenic behavior.

Five of the seven youth who entered AYI from institutional programs had experienced 11 or more placement changes prior to that time (Mary, Carol, Gloria, Jim, and Gretchen). The other two experienced multiple placements in a psychiatric institution for their schizophrenia (Tony and Alexis). The two youth under threat of institutionalization included a 14-year-old (Jill) who had already engaged in a 2-year odyssey through foster homes, group homes, treatment facilities, and correctional facilities throughout Alaska; and an 8-year-old (Ned) who was headed for the cafeteria of established residential services (i.e., intensive treatment centers, group homes, detention centers, and psychiatric hospitals) far from his home community.

Table 1 shows the specific characteristics of these youth, their age of entry to the service delivery system, the age of entry into AYI, the duration of AYI services, their current status with AYI, their age at interview, and their DMS-III diagnosis(es).



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Table 1 Age at entry and exit of service provision, service duration in years, and DSM-III diagnosis

Name	Age at Service Entry	Age: AYI Entry	Duration: AYI Service	Age: AYI Discharge	Age at Interview	DSM-III Diagnosis
Alexis	13:6	16:0	1:4	Active	17:4	Schizophrenia
Gregory	14:10	15:5	3:1	18:6	18:9	Schizophrenia
Tony	16:8	18:4	2:8	21:0	21:1	Schizophrenia/Organic Brain Syndrome
Gloria	9:0	11:5	1:8	Active	13	Conduct Disorder/ Dysthymia
Jim	13:3	14:7	2:5	17:0	17:6	Conduct and Gender Identity Disorders
Mary	2:0	16:6	:9	Active	17:3	Borderline Personality/ Conduct Disorder
Gretchen	14:4	15:9	3:5	Active	19:2	Borderline Personality/ Depression/ADHD+
Ned	5:4	8:8	1:0	Active	9:8	Conduct Disorder/ Oppositional Defiant/ ADHD+
Carol	7:6	17:5	1:2	18:7	19:0*	Conduct Disorder/ Substance Abuse
Jill	12:6	14:6	3:5	17:11	18:3	Conduct Disorder/ Multiple Personality
Median	12:11	15:7	2:0	18:7	17:11	

<sup>\*</sup> Age at follow-up. Not able to arrange for personal interview. + Attention Deficit Hyperactivity Disorder

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#### To what extent was AYI an alternative to long-term residential care?

In all but one case (Gretchen), AYI has been a successful alternative to long-term residential care. For six youth (Mary, Carol, Tony, Jim, Gloria, and Alexis), AYI was the vehicle for reintegrating and socializing them to their own or nearby communities as they came from restrictive institutional placements. Without AYI, they most likely would have been transferred to other long-term residential programs. For two youth (Ned and Jill), AYI was the *only* alternative to long-term restrictive institutional placement. For one youth (Gregory), it was unclear whether he would have been placed in residential care without AYI services. The dogged determination of his family was an essential factor in precluding residential placement. At the time of this study, all nine of these youth had been living in open settings in their respective communities from 1 to 3 years. In the one exception to AYI's being a successful alternative to residential placement (Gretchen), a failure in a community placement resulted in 2½ years of institutional placements (mostly out of state). At the time of the interviews, the return of this youth to the community had been of too short a duration to tell whether or not it would be a successful alternative.

#### What was the success of AYI?

Services coordinated, planned, and implemented through the Core Services Teams under the auspices of AYI had been successful in assisting 9 of these 10 youth in becoming more independent and responsible, socially appropriate, and acceptable to themselves and their communities. AYI was able to stabilize all but one of these youth in an open community setting (most in their community of tie) within the first 6 months of placement. This was a major issue for seven youth who had been constantly running away from most prior placements, living on the streets, and being victimized by others. Two of the remaining youth were unable to run away, having been placed in secure psychiatric facilities for their schizophrenia. The tenth youth was the one with the family that was determined to keep him at home and, with AYI's support, he never left his home or community for residential treatment. These and further results are summarized in Table 2.

In almost every case, AYI was able to reengage youth in the educational system in a consistent and highly beneficial manner. Prior to entering AYI, all but one youth had a history of ineffective interaction with the educational system, resulting from emotional disturbance. The three in school at the time of this evaluation (Ned, Gloria, and Alexis), had achieved successful reintegration with their classmates in mainstream schools and classes for most, if not all, of their course work. Two of the three were achieving consistently high marks. Five of the older youth had either successfully graduated from high school or had obtained their GEDs (Mary, Carol, Jill, Gregory,



Table 2
Outcome data at the time of interview

Aiexis	Living at home, attending regular school.
Gregory	Living at home, high school graduate, plans to attend college in the fall.
Tony	Living in an apartment with mental health aftercare services.
Gloria	Living in a specialized foster home, has completed regular school year, and is presently attending summer camp with non-disabled peers.
Jim	Independent living with full-time job.
Mary	Living in specialized foster home with her baby, has completed her GED, and plans to attend college in the fall.
Gretchen	Living in a supervised apartment, has completed her GED but is presently experiencing an unstable adjustment and may require more intensive services.
Ned	Living in a specialized foster home, has completed regular school year, and is attending summer camp with non-disabled peers.
Carol	Independent living with her baby, has completed her GED, and is awaiting the release of her husband from a correctional facility.
Jill	Independent living with her boyfriend, is pregnant, has completed her GED, and is working full time.



and Gretchen). One youth (Tony) was sufficiently organically impaired to preclude obtaining a mainstream high school degree and the remaining one (Jim) planned to begin working on obtaining his GED as a personal goal.

With the exception of two youth, AYI was very effective in providing these highly agitated, disturbed, and disturbing youth with extremely committed, responsive, persistent adult care providers. In almost all instances, these care providers were able to develop extremely significant, trusting, respectful, and enduring relationships with the youth. Almost all of these people continued to be seen by the youth, even after independence and service termination. The youth, by self-report, saw these individuals as significant resources should they need assistance or support in the future. The two exceptions include one youth who never left home (Gregory) and one youth who had rejected all of her caretakers as well as her family (Gretchen).

AYI had been largely successful in providing services and training to enable the older adolescents to obtain and maintain personal independence as young adults without engaging in their previous self-abusive, bizarre, aggressive behavior, and/or dangerous habits of drug abuse, prostitution, homelessness, or crime (shoplifting, assault) in order to survive in open community settings. At the time of the review, five of the eight older youth (Jill, Jim, Gregory, Tony, and Carol) had been discharged from AYI, all of their own volition (see Table 1).

Although all of the discharged youth were living in the community, Tony required follow-along mental health services, and Gregory had just returned home from a summer supervisory job at a forest camp and was preparing to attend college in the fall. Jill and Jim had stable jobs, and Carol was married with a new infant, living on AFDC payments while her husband was serving a sentence in jail. Jill was living with her boyfriend, expecting a baby in the fall, and planning to get married in the near future. Her boyfriend also had a stable job.

These five young adults had received from 1 to 3 years of community-based services (median 2 years) in lieu of expensive, restrictive, continued institutional treatment. Four of these youth were interviewed from 1 to 6 months post discharge (one was not available for interview) and, without exception, they were confident of their ability to continue to live unsupervised in the community. Jim expressed the need to acquire further vocational, educational, and counseling services for himself as his limited educational accomplishments left him with very limited vocational opportunities. Gregory had learned to self-medicate and manage his own psychiatric symptoms while going to school and working in mainstream settings. In addition to being confident of their ability to make it on their own, Jill, Jim, and Gregory were aware of their ability to obtain further services, support, or assistance should they need it, and they remained in active contact with their support networks. Tony was accessing support on a regular basis, and Carol periodically called her case manager to maintain communication.



The five youth still receiving active treatment in AYI at the time of the review included the two youngest, Ned, age 9, and Gloria, age 13, who were continuing in specialized foster care after completing a very successful year in their foster homes and at school, both participating in mainstream summer recreational programs without their labels (i.e., without staff or other kids knowing that they were called severely emotionally disturbed (SED)). These two had received the shortest duration of AYI service and had responded relatively quickly to the provision of structured, consistent, and coordinated programs at home and school with the elimination of their highly aggressive and disordered behavior. Unlike previous (or imminent) institutional and residential treatment placements, their special foster homes and regular school placements did not provide them with a large cadre of disordered peers with whom they might continue to act out and from whom they could learn even more ways in which to act seriously emotionally disturbed. Several youth described to the interviewers that placement in congregate treatment facilities served as a training ground for new and more deviant or unacceptable behaviors. The remaining three youth, ages 17 to 19, who were still in AYI at the time of this evaluation (Alexis, Mary, and Gretchen) had all been returned from very restrictive, lengthy institutionalizations a relatively short time before and had been receiving community-based services as an alternative to lengthy institutionalization for only 3, 6, and 12 months respectively. Gretchen, who had been in the community for only 3 months, was having a difficult time, creating disturbances and demanding reinstitutionalization. Since many of the reviewed cases demonstrated that it took about 6 months of testing and disruption before case stabilization took place, her behavior could be an anticipated outcome at such an early stage of reintroduction to the community and to more open service provision.

The other two, after very poor prognoses in their respective institutional settings and extremely depressed and regressed behavior, were making exceptional adjustments to community living. Alexis was living at home with his family in his native village after an initial 6-month period during which he acted very bizarre, was extremely recalcitrant, and very difficult to manage. He had achieved reintegration into regular classes and was participating freely in his community, school, and home. Mary was exhibiting very appropriate maternal behavior at her specialized foster home with her new infant after being back only 6 months from lengthy institutionalization and a period on the streets during which she engaged in repeated suicidal gestures, serious self-abusive behavior, violent assault, sexual promiscuity, and serious drug abuse. In addition, she had completed her GED, gave the commencement address at her graduation ceremony, was working towards moving into her own independent apartment, and was planning to enter college in the fall.

In summary, in all but one case, AYI was successful in stabilizing the behavior of the youth within normalized community settings, eliminating runaways from their residence or home setting, and eliminating or reducing to low levels their acting-out



behavior. Five youth were able to receive educational services in regular school settings and to participate in normal educational and extracurricular activities with their peers, while four of the older youth received GEDs. One youth, post school age at the time of admission to AYI, was too affected by his psychiatric disability to be able to engage in educational activities.

### How likely is it that the youth would have improved without AYI?

Since this review of AYI cases is not a controlled, comparative study, the answer to this question can only be conjecture. One could say that the youth improved in their behavior and adjustment while under the auspices of AYI as the result of growing older, aging out of their adolescent rebellion, and moving towards and into more adult activities and autonomy. Or one could infer that the dramatic changes that were seen, usually after about 6 months of treatment, were due to regression towards the mean (i.e., AYI received them when they had reached the height of their acting out and they could only move in one direction – down). There are several indicators which suggest that the improvements in behavioral adjustment evidenced by 9 of the 10 youth were not entirely due to maturation or to regression towards the mean.

First, most of the youth continued to display the same behaviors during the first 6 months of AYI community-based treatment that they had displayed previously, the very behaviors which were the reason for admission to AYI service in the first place. In most instances, the youth's behavior change occurred only after they had engaged in heavy testing of the rules and attempts to disrupt, destroy, and/or run away from their new placement. The changes in behavior came when, unlike in former situations, their behavior did not result in a new placement nor in an opportunity to run loose on the streets for long periods, but rather in their care providers' coming after them and returning them to their homes.

At school as well, the change in adjustment came gradually over a period of time when the school worked closely with the Core Services Team, instituting a highly structured behavioral program that was not easy for the youth to avoid. The youth also found that it was equally hard to get themselves thrown out, suspended, or expelled.

Second, the two youngest (age 10 and 13) were those for whom the turnabout was quickest, easiest, and most pervasive. While both of these youth were entering into an adolescent rebellion/autonomy phase at the time of the study, they were not exhibiting the same signs that the others in the study had been demonstrating at that age when they were running through most placements and services in the service delivery continuum. The maturation argument would suggest that the younger ones would



persevere the longest in maladjusted behavior, but, in fact, the opposite was true. This is an argument for stabilizing a youth's life as early as possible.

Third, three of the older youth had clear psychiatric diagnoses of schizophrenia and were actively delusional and psychotic during the initial stages of the AYI intervention. In two cases, regression in the hospital was followed by eventual stabilization in the community. While some maturation or remission may have been occurring, it seems highly questionable that it would have taken place in the psychiatric hospitals where the youth had been placed for an extended period of time and where, in fact, they were getting worse. For one (Tony), no remission actually took place, rather he learned to maintain a marginal adjustment in the open community (and the community learned to deal better with him). The two others continued to be delusional and openly psychotic during their initial months with AYI. At the time of the interviews, cyclical episodes were still occurring for one, but he had learned to use behavioral and pharmacological means to control them.

Fourth, reports from longitudinal studies of youth with similar presenting problems suggest that, over time, they do not necessarily get better. This is indicated by the preliminary results of the National Adolescent and Child Treatment Study conducted at the University of South Florida (Silver, 1993).

Fifth, it is clear from an examination of the case studies that AYI Core Services Teams had to make major service modifications to respond to the needs and behavior of these youth during the time they were receiving AYI services. The magnitude of the service changes that were, at times, required indicated that the youth were not getting better primarily as a function of age. Each youth received intensive, individualized services which were tested extensively and intensively by that youth. In each case, it took at least 6 months to obtain any apparent "turn around" or positive response to AYI services and coordination. In one case, a lasting positive response or decrease in high-intensity behaviors requiring restrictive placement had not occurred, yet in this case the youth had not been out of her highly restrictive institutional placement for more than a few months.

Finally, the youth themselves and their families assert that they benefitted substantially from the opportunities, relationships, skill building, and stabilization of their lives that took place in normative settings near or in their home communities through the work of the AYI Core Services Team.



# What AYI services and policies were most commonly associated with successful outcomes?

The key features and characteristics identified as being most critical to the success of AYI by the individuals interviewed and by analyses of the 10 case studies are as follows:

Overall AYI philosophy. Almost everyone interviewed spoke about the importance of the overall AYI philosophy. In general, they were referring to the unconditional commitment to a tough child or youth, the interdisciplinary teamwork, the commitment to least-restrictive, community-based services, the flexible funding and flexible services, and the individualized and child-focused treatment plans. It was clear that this philosophy was substantially different from "business as usual" in service delivery and it generated a high degree of enthusiasm and morale.

Individualization of planning and service delivery. An essential component of the success of AYI was fitting the services to the youth rather than trying to fit the youth to a program. Creative examples of this include placing a youth in a 24-hour-staffed apartment rather than in a group home, providing a paid friend for social integration, having a youth live in an apartment with an admired mentor or peer, and having a youth live with a young couple and their child in order to learn parenting skills.

Unconditional commitment to the child. The best youth outcomes were associated with providers whose attitudes reflected unconditional care, "no matter what the kid does." In general, staff stayed with the youth, retrieved the youth, negotiated with the youth, and stood up for the youth through the most difficult times. Through this process, they developed mutual, trusting relationships which helped to minimize the multiple placement shuffle. Staff refused to give up.

Multidisciplinary teamwork. Core Services Teams, typically comprised of the youth, parent(s), service providers, and key agency representatives from mental health, education, and social services, made decisions on the basis of consensus and shared responsibility. Although the size and constituency of treatment teams varied considerably, successful outcomes were highly related to effective teamwork and coordination, in some cases, in a dramatic fashion.

Flexible funding. AYI had the ability to energize services and systems with flexible funds which "followed the youth." The Core Services Teams were able to use flexible funds to add critical resources in a timely manner, frequently preventing a transition into a more restrictive service. These included such resources as a temporary one-on-one aide in a school or residential setting to assist with a crisis, transportation to maintain continuity in school during a change in residence, tuition for summer camp, and emergency respite for a caretaker.



Staff skilled in promoting youth trust and respect. In several cases, there was dramatic improvement in a youth's attitude and behavior, exemplified by a sharp reduction in the number of placements, AWOLs, and crisis episodes. These changes were clearly associated with the development of a strong bond between the youth and a provider. These providers (e.g., a foster parent, an aide, a group home parent) were strong advocates for the youth, skillfully listened to their concerns, and stuck with them through some very difficult times.

Excellence of direct care personnel. The key factor in youth recovery often was the quality of direct-care staff. AYI was frequently able to recreexcellent personnel who were experienced and/or were well trained in working with challenging, disturbed youth; they could provide structure and consistency while also being flexible and drawing on the youth's strengths and interests.

Structured behavioral contingencies. In most cases, some form of behavioral contracting or contingency management was in place at home, and often at school, assisting the youth in developing self-control and a more respectful relationship with providers. Providing structure and limits that required responsible behavior and opportunities for restitution were related to successful outcomes, particularly when these factors were perceived as fair by the youth.

Community-based services. Almost all of the AYI services were provided in settings in the community that were less restrictive than long-term recidential care. This provided the youth with the greatest opportunity to learn the skills that are essential for autonomy and self-sufficiency. By learning to control their behavior and achieve success in more natural settings, youth are more likely to cope with the inevitable conflicts that will arise after services are removed.

Developing crisis plans. Over time, AYI became very creative and adept at developing crisis plans that made it possible to avoid placing the child in a secure facility. In general, this involved the timely addition of trained personnel to defuse, or at least stabilize, a situation. AYI was less successful in implementing a crisis response that required the participation of another agency (see below).

# What might improve the AYI service or improve an individualized, wraparound delivery system?

Increase training. Much of the training that took place for the parents, administrators, advocates, and service providers in these 10 cases could be characterized as fragmented, crisis-promoted, on-the-job training. This is understandable given that AYI had to invent much of the wheel in this effort to serve the most difficult youth in their communities and villages. Clearly, any replication of the AYI program would



be rendered more effective through a more prolonged and proactive training program that incorporated the learnings of AYI.

Begin AYI services sooner. The findings in this study strongly imply that even greater progress could have been made if AYI services had begun earlier in a youth's life. In the opinion of several people who were interviewed, AYI services should begin at the point where long-term residential care is being considered. There is little indication that any progress made was facilitated by long-term residential care, either in state or out of state. This opinion was shared by all but one youth, all parents, and almost all providers. A substantial number of people interviewed felt that the long-term residential treatments that took place were actually harmful. Even in those cases where residential treatment appeared to produce no effect, there was concern that it consumed time during which progress could have been made through individualized services.

With respect to starting sooner, it is necessary to establish clear criteria for inclusion. There is ample justification for including any youth for whom existing or anticipated costs are equal to, or exceed, the costs of individualized services. But when starting sooner means a significant increase in the cost of services, it is necessary to try to target those youth who would otherwise receive more costly services. It is unlikely that any service delivery system will be able to afford a relatively major investment at both ends of the continuum of services. Given the struggle to obtain new resources in the area of human services, it is more practical to try to shift the way resources are spent than to add new ones.

In addition to starting AYI services at the point that a sustained residential placement is being considered, AYI should be viewed as a way to stop frequent changes in placement. While some placement change is inevitable, extraordinary efforts should be made to prevent repeated placements similar to the dozens of placements that occurred prior to AYI in many of the cases that were reviewed.

Develop a more controlled and flexible crisis response. Some AYI service providers spoke of having inadequate resources to respond in a timely fashion to infrequent but extreme escalations in aggression towards self or others. The typical response was to call the state police and/or to try to have the youth admitted to the state hospital or correctional center, depending on the incident. On several occasions, the police did not respond in a timely fashion because the incident did not involve a potential felony (e.g., a smashed door or wall). The problems with the residential placements were an inability to meet admission criteria, particularly in a timely fashion, or, once admitted, an inability to influence discharge, resulting in an unnecessarily long stay.



The service providers in question appeared to be seeking a crisis response that would safely stabilize the youth (with their participation), and would enable them to return the youth to the AYI residence in order to work through the problems that precipitated the crisis. On at least two occasions, the state hospital functioned very successfully in that capacity. Any cooperative agreements which would facilitate that type of crisis response would be helpful.

Wherever the need, continue AYI services into adulthood. While it is apparent that some youth could have benefitted from an earlier admission into AYI, it is also clear that many youth will need some services well into adulthood. Given the progress that has been made, it will be unfortunate if these youth regress because adult services are fragmented, inadequate, or unavailable.

Avoid grouping multineed youth. For several of the youth receiving AYI services, there were occasions when they were placed with other multi-need youth. This happened most during times when AYI was recruiting specialized foster parents or when there was a need to stabilize a youth following a crisis. In most of these cases, it did not appear that the group component facilitated progress and, in some instances, it was clear that such placement served as a barrier. While it may be less expensive to group youth together, in the long run it may be less cost effective. More emphasis needs to be placed on the utilization of non-multineed peers.

Establish financial security for direct care staff. A common concern among the direct care staff (e.g., foster parents, professional roommates, mentors, apartment supervisors) was financial security and long-term benefits. In general, they loved their work. They had more control, flexibility, and support than existed in the categorical service delivery system. They also received higher salaries. But they tended not to have much long-term security. As one worker put it, "It's great while it lasts, but as the youth makes progress, you can work yourself out of a job." Many excellent direct care staff were interviewed during this study. They might function even better if they knew that unconditional care also applied to them.

Other recommendations. Finally, a number of recommendations were mentioned less frequently. They included collecting more timely outcome data to facilitate adjustments in services, increasing participation of the youth themselves in the development and modification of their service plans, and increasing communication with the primary parent or relative, especially when she or he is located a significant distance from the youth.



#### Conclusions

In general, there are two striking findings in this qualitative evaluation of the Alaska Youth Initiative. One is that remarkable changes took place in 9 out of the 10 youth who were studied; the other is the radical difference in the way the youth in this study were served.

With respect to the progress of these youth, eight were now young adults living in the community. All but one were living fairly independently, having gained significantly in self-respect and self-confidence in their personal future. In addition, they had gained personal empowerment. They had acquired many skills: skills in daily living, skills in self-control, some educational and work-related skills, skills for finding and using assistance from social programs, and skills in accessing community resources. Those with serious drug dependencies appeared to have broken their drug habits. They also had built the beginnings of meaningful social support networks.

The two youngest of the 10 remained in specialized foster homes, also having gained enormously in self-control, self-respect, and social skills. Both of these young people had access to activities and opportunities within the mainstream culture that would enable them to learn and acquire needed skills, including basic academics, which may eventually empower them to succeed as adults.

With respect to the service model, it clearly differed from "business as usual." Given that most of the youth in this study had behaved their way out of the least restrictive, and in some cases the most restrictive services that were available, an anticipated response could have been that more isolation, more restriction, and more medication were called for. Instead, these youth were moved into the community and, with a striking amount of commitment, creativity, and ingenuity, services were administered on the basis of their individual needs.

The critical question as to whether or not the service model caused the remarkable change in behavior cannot be answered in this evaluation. Nevertheless, the qualitative evidence contained in the case studies that follow generates some promising hypotheses. While lengthy institutionalization or residential treatment may have provided a venue in which youth could learn some new skills and some self-control, including the breaking of drug habits, it is difficult to see how that would translate directly and successfully into community living, effective work habits, abstinence in an open setting, and adequate social skills. It is also difficult to see how an individual builds self-confidence, self-respect, and confidence in his or her future after spending lengthy periods of time divorced from the realities and exigencies of independent community living.



Ultimately, the belief in the viability of treatment in a closed setting is based upon the assumption that the problem is "in" the person, rather than that the problem lies in the interaction and interdependence of the person and his or her several environments (i.e., school, home, work, social network, and community). Individualized, wraparound services are based upon the belief that an individual's best hope for treatment is in receiving support in the real context of his or her life, working through issues while living in and dealing with those real environments. In 9 of the 10 cases in this study, the second premise was emphatically demonstrated. Even the 10th case demonstrated that a lengthy institutionalization may bring dangerous, self-destructive behavior under control in that specific setting, but may do little to help translate this into the community setting. For this individual, the community treatment and rehabilitation effort had just begun.

A final word, however, is that all the youth in this study remain at risk, at risk for losing the fine edge in their personal and social adjustment. Most continue to live economically on the margin of society, with no great prospects of being able to achieve financial or personal success as measured by most of society. Many of their support networks are individuals who also live a marginal social and economic existence. It is unrealistic to believe that a few years of successful, respectful, stable, interpersonal and community living in the later years of their adolescence can inoculate them against the vicissitudes and personal challenges that they will undoubtedly encounter in the future. At the time of the study, they felt empowered and were knowledgeable about services, how they worked, and how to seek support and assistance if they felt they needed it. Whether that is sufficient to sustain continued, untroubled adult independence is certainly uncertain and questionable.

The two youngest in this study had the possibility of experiencing a stable, supportive, and positive socializing environment throughout a much longer segment of their developmental period than the older youth. They have the opportunity for successfully practicing more positive social and personal behavior and reaping the benefits over a much longer period of time. They also have the opportunity to develop and maintain positive and stable role models and social supports for a longer period while they build the skills which may afford them a greater chance to access the available models for successful lives as adults. Their prognosis should justifiably be better than that of their older peers. Nevertheless, as with other persons with disabilities, communities need to expect and to be prepared to provide supports from time to time in order to facilitate their efforts to live independently. As AYI has demonstrated, success can be achieved, one kid at a time, one step at a time.

# **CHAPTER 3**

# Three Cases of Schizophrenia: Three Individualized Responses

The three young men described in this chapter had one thing in common, and one thing only: a psychiatric diagnosis of acute schizophrenia with adolescent onset. Two of these youth had one other thing in common: their initial unsuccessful treatment in a closed psychiatric hospital.

These three young men were from very different socio-cultural backgrounds, one from a cultural background; as divergent from the other two and from the general population as can be imagined. The youth also had totally different etiologies for the disorder, at least with regard to precipitating environmental circumstances, and they received quite different individualized services after acceptance into the Alaska Youth Initiative.

What follows are three separate stories of individualized interventions and individual outcomes for these three youth with diagnoses of schizophrenia. At the time of the review, all three were being served in their home communities with decreasing levels of supervision and intervention. Two were leading age-appropriate lives with their families while the third was living alone in his own apartment with some adult services for persons with chronic mental disabilities.

#### Case: Alexis Bill - The Setting, Bush Alaska

Alexis is a young man from a small, remote village in the Arctic region of Alaska where he grew up with 300 friends and extended family members. Alexis had spent his entire life in this village, leaving only to hunt and fish with his family in the traditional manner. He spent every summer in the family "fish camp" along a major river where they harvested their annual supply of fish from the salmon runs which take place from June through August, then returned to the village for the long and dark Alaska winters. In the village, Alexis and his friends attended a modern school staffed primarily by nonnative, Euro-American teachers from "outside" Alaska who lived there for the nine school months and retired quickly to the "outside" at every opportunity. Due to a career incentive to teach for one year in the bush, many teachers were new to the village each or every few years.



There were no roads to this village and no suburbs. The village was a cluster of small, wooden, three-to-four-room houses built on stilts (the permafrost precluded building on the soil as it would melt and the building would tilt or fall). Each house had an open living area that included the kitchen, a dining area, a sitting area, and one or two small rooms for sleeping. The homes were simply furnished; they had electricity, running water, an early vintage washing machine (circa 1960), a stove, a small kitchen table with chairs, a couch, and a few stuffed chairs around the TV set. Sleeping quarters were located off to the side. Families of 5 to 10 members lived in these small, unpainted, undecorated wooden homes which were connected to each other by raised wooden plankways. These plankways served as sidewalks so that people could walk to their neighbor's home without sinking into the spongy, often muddy, earth during the warmer season. One rutted, unpaved road less than a mile long went from one edge of the village where the school was located, past the cluster of wooden homes fronting the river, to the airport at the other edge of the village.

The airport was a small field marked by a single orange wind sock which looked much like a large man's woolen sock hung on a bent metal pole located next to a wooden three-sided shelter resembling an unpainted bus stop shelter without a bench. The airport was designed for single-propeller bush planes, ubiquitous in Alaskan transportation. This is how people representing services from the dominant culture accessed the village. There were few scheduled flights to the village, but bush pilots were available to be hired from the district town to transport people to and from the village upon demand, not inexpensively, if and when the weather permitted.

On the infrequent occasions when people visited the village (usually educators and health workers), they frequently left the same day as there were no accommodations for "outsiders" in the village. In the event that visitors had to stay longer, if they were fortunate they were invited to stay with a teacher's family. Otherwise, they simply slept on the carpeted floor of one of the modern classrooms in the school. If villagers ever saw someone they didn't know in the village, they knew that that person belonged to the school. It wasn't uncommon for someone raised in one of these villages to have rarely, if ever, seen a stranger: someone that they didn't know or someone whose business in the village wasn't understood.

Among the village houses, and barely distinguishable from them by its outside, was one general store containing a small supply of basic foods and necessities sold at high cost to the villagers.

The real road to the outside for most villagers was the river. It connected the village to other distant villages as well as to the district town, the latter being the hub for state and federal services to Village Alaska. Many families owned open, wooden or aluminum 14'-18' boats with outboard motors for fishing and transportation during the warm months. They used snowmobiles for transportation during the long winter



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months when the river was frozen. In winter, the frozen river served as a highway to neighboring villages, complete with snowplows to clear the way for the many pick-up trucks that drove to and from the district town.

Fall and winter were traditionally for hunting caribou, although in recent years it had not always been easy to find the herd. Other game had become scarce, too. Nevertheless, hunting, fishing, and gathering berries for subsistence living was still the major occupation of most villagers. This was supplemented by the usual assortment of entitlement programs available to most low-income Americans. These programs included welfare, food stamps, social security insurance, unemployment, and the Alaska positive income tax. With respect to the latter, each Alaskan receives a yearly cash payment from the state's oil profits. For the particular year in which this study was done, the payment was approximately \$1,000. These entitlements provided villagers with the means to participate in the cash economy by enabling them to pay for home heating, gasoline for their motors, clothing, housewares, additional food, fishing and hunting supplies, TVs, boats, all-terrain vehicles and snowmobiles.

There were few jobs in the village. The modal adult condition is unemployment, which accounted for over 90% of the households. Paid jobs, as in the Western cash economy, are a rare handful: one man is a police officer (a young man of the village), two men are members of the National Guard, one adult is a store clerk in the general store, and a few women are aides in the school. Other paid employment requires villagers to leave the village and live and work in the district town.

This district town, a community of 3000 people, is the closest outpost of the dominant Western culture. This outpost, which is located near the coast, is closer to what formerly was known as the USSR than to most of the populated areas of Alaska. It is the location from which the missionaries worked with the Native villages early in the century and is accessible by boat from the ocean for fishing, hunting, gold seeking, and other economic interests of a Western culture bringing "civilization and progress" to a technologically primitive, subsistence people. The district town is the base of operations for administering the services of a modern state to the many inaccessible villages scattered throughout the bush in northern and western Alaska.

The district town contains the district health service and hospital, school district offices, a fish processing plant, a few unpaved roads connecting all the homes and businesses to each other and to the airport, a mental health clinic, a few churches, a restaurant on the order of a '50s diner, a snackbar, a general store like a very small Ben Franklin store, another small general store which is a native cooperative, a small hotel and a few bed and breakfast homes for members of the dominant Euro-American culture who come through on business (e.g., bush pilots, teachers for teacher training, health workers, mental health workers, engineers, itinerant judicial staff), the nuts and bolts emissaries of the dominant culture reaching out to the small villages of Bush Alaska.

There are no bars as the district town is officially "dry," however, that doesn't preclude the appearance of some raucous drinking along the more populated streets, particularly on a Saturday night.

This town owed its somewhat bleak appearance to an environment unprepared to sustain with grace, dignity, or stability, permanent roads, cars, modern houses, foundations, sidewalks, or a human population of any size. Paved roads quickly caved into the permafrost. Plumbing had to be above ground in giant, galvanized, heavily insulated pipes that connected the houses in a giant maze.

The surrounding terrain was flat. No trees and few shrubs except for those that clung to the river bank grew in this environment. During the warm months, the ground beneath the grasses indigenous to this arctic region was easily turned to mud by the activity of many people walking upon it and wheeled vehicles running over it again and again as happens in any town. Unlike the very small native villages which nestle unobtrusively among the riverbank grasses, creating a less intense impact on the tundra and permafrost, the district town had not succeeded in becoming graciously integrated into this fragile environment.

Driving cabs appeared to be a major form of employment in the district town. Cab drivers were highly visible, driving old dilapidated automobiles around the muddy, rutted streets, transporting people about town and to and from the airport. The airport had several landing strips to accommodate modern, if small, jets, and a small air terminal with an indoor waiting room. Airline staff were mostly non-Native. The persons using this gateway to and from Bush Alaska were mostly sportspersons coming to fish or hunt, state and federal officials, and businessmen.

#### Background

The world of Alexis Bill<sup>1</sup> was the world of his village; the family fish camp on the river, the tundra, and the traditional village life of his people in the Arctic. Alexis and his friends' main contacts with modern society were through TV and their Western school. They watched the same TV programs seen by everyone else "outside" Alaska in the "Lower 48." Their school, a huge, single-story brown frame warehouse that

<sup>&#</sup>x27;The derivation of names of Native Alaskans is interesting. When the missionaries arrived at the turn of the century to "save" these people from their "heathen . . . ways," they were, of course, unable to pronounce their names. They therefore called them by simple, Anglicized first names such as Dan, Bill, Jim, and Ruth. When Dan, Bill, and Ruth had children, they were given addition?' simple Anglicized or Russified (a strong influence in this region) first names with their parent's first name now becoming their surname, as has been done historically in many cultures. Hence Bill's son, Alexis, became know as Alexis Bill.

looked like it might have been dropped from the sky onto its many stilts beside the river bank, was, in fact, very modern and up to date. It had a gymnasium; classrooms with wall-to-wall, indoor-outdoor carpeting; computers; and a complete modern kitchen with all the modern appliances including a microwave oven. It boasted new desks, new educational materials, and a long, handicap-accessible wooden ramp that led up from the river to the main entrance, even though it looked next to impossible for someone to negotiate in this environment in a wheelchair. The school met all federal specifications.

This was the world of Alexis Bill from the time he was an infant until the time, at age 13, he began manifesting serious, aberrant behaviors which his family and his neighbors ignored in the traditional manner, and then shunned. However, Alexis' behaviors became so egregious and threatening that they (and he) could no longer be totally ignored. His bizarre and wild behavior at school, where he had been officially labeled seriously emotionally disturbed, resulted in a cry for help from the school teachers to the district office. Shortly thereafter, Alexis was transported by airplane from his village life in the tundra of Alaska to a psychiatric hospital many hundreds of miles away for modern psychiatric treatment. Having been diagnosed as having schizophrenia, Alexis' treatment consisted of pharmacotherapy with some psychotherapy provided by therapists from the dominant culture who were reared and trained outside Alaska.

After a few months of treatment, Alexis was rather abruptly returned to his village and his family with the primary treatment consisting of his psychotropic medication. Mental health services were available on an outpatient basis from the district town, but his family, like many others in the villages, did not access that service more than a few times, whether due to the difficulties and expense of transportation to the district town or to cultural disinclination to go to a clinic for therapy.

Alexis continued to frighten his friends, neighbors and school personnel with his bizarre talk, full of sexual and violent content, and with his weird and threatening behavior. He was still an outcast, feared, ignored, and shunned by his community. He seldom went to school, refused to take his medications, and did not bathe or take care of himself. School teachers and officials were terrified that he might choose to come to school, and he was expelled.

Alexis was soon returned to the distant psychiatric hospital for more inpatient treatment. As had been true during his first hospitalization, there was no direct contact between the hospital and Alexis' family, nor between the village or the local school representatives and the psychiatric hospital staff. There was enough contact between the school district office representing the village school and the mental health office, whose outreach worker had occasional contact with the village and the village tribal council, to inform the hospital that neither the village nor the school was able to cope



with Alexis. Nor did they feel they could provide any appropriate services for him, should he return home.

When Alexis returned, anyway, to his village for the second time, he was 14 years old and his behavior steadily worsened. His wild and bizarre behaviors in the village and at school, which he rarely attended, reached a climax when he killed a neighbor's dog for no apparent reason, and then attacked and tried to kill a close relative with a knife. Everyone at school and many in the village were terrified of him. The villagers and the school cried out again for help and once again Alexis was transported to the psychiatric hospital, this time for a year and a half.

During this third, and most lengthy, hospitalization, Alexis steadily declined. In the closed psychiatric hospital, Alexis hallucinated, became extremely frightened, and withdrew. With no contact with his family or with others he knew, he had dreams that a huge atomic bomb had been dropped on his village and his village had disappeared from the face of the earth. He also dreamed that a giant black wolf came to his village and devoured his entire family. Despite continuing medication and psychotherapy, Alexis became more depressed and steadily regressed. It was under these circumstances, at age 15, that the clinical director of the hospital referred Alexis' case to AYI.

#### Alaska Youth Initiative: Services and Outcomes

It took AYI several months to develop a Core Services Team and implement a treatment plan. An AYI administrator visited the village, Alexis' family, and the village tribal council, and then talked with school officials and mental health workers in the district mental health clinic. A core team, including Alexis' parents, was formed from these parties. The team's plan was to return Alexis to his home and to provide supports to his family and school right in the village. Through the help of the tribal council, the team sought to hire a full-time aide from among the village people to implement the team's plan. The aide's role would be to provide direct services to Alexis and to be a liaison with professional mental health and special education services from the district and state offices. An itinerant mental health worker would provide occasional support services to the family.

The aide's role was to see that Alexis took his prescribed medication on a regular basis, that he got up each day to attend school regularly and promptly, that he remained in school, somewhere, throughout the school day, and that he returned to his family home after school. When the family had difficulties or problems, family members could call upon the aide to help out or give them personal support. The cultural way of dealing with deviant behavior, by ignoring and shunning, was to be replaced by



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strong demands for performance of daily living and school activities with no tolerance for bizarre and deviant behavior.

The tribal council initially sought to hire a man for the aide position since Alexis was full grown, very strong, and potentially violent. However, a woman of the village applied for the job and was selected. This woman had a somewhat unusual background (for the village) and an unusual physique for her ethnic group. Clara was a large, very strong, very strong-minded and determined woman. She was tall and husky, which was rare among her people who are generally of small stature. Clara had grown up in a nearby village and had a Russian grandparent to whom she credited her large stature as well as her personality, also unusual for this culture. She was outgoing, loud, assertive, no-nonsense, and directive, in stark contrast to the culturally supported, reserved and nonassertive demeanor of many of her people.

Many people from the village appeared soft spoken, nondirective, quiet, and fatalistic. They engaged in less direct eye contact and were more indirect in their social communication than is common for most American citizens. They also did not share the Western sense of time urgency; they adhered to few set time schedules and their actions and plans were not as time-limited, time focused, or outcome-oriented as those of many in the dominant culture. This was identified as a problem by service providers from the dominant culture in their dealings with them. The villagers also appeared to be nondirective in their expectations, demands, and dealings with each other and with their children.

Clara had a commanding presence, was not reluctant to express her ideas, and had many strong opinions. She was exceptional in several other respects, too. She had left her village to attend high school in a distant Alaskan mainstream town, had succeeded in the Western educational system, had graduated from high school; and had gone on to college outside Alaska. However, like many before her, she found that she was unable to deal with the significant lifestyle differences she encountered "outside" without support from others of her culture, so she returned to her village after one semester. She was also different in that she had some police training and experience before she came back to live in the village. She was eager to be hired to be Alexis' aide, and the tribal council and the core team, including Alexis' parents, were happy to have found someone willing to take on the task.

Alexis was returned to the village shortly before the new school term began in late August of his 16th year and, according to the district school office, shortly after it had received notification from the psychiatric hospital that Alexis would need continued long-term inpatient psychiatric care due to his schizophrenia. The local school personnel were very reluctant to have Alexis return. They were physically afraid of him and maintained that he could not be handled in the village school. Upon his return, Alexis was functioning academically at a third grade level, although he had

attained a higher educational level than that before he had Legun his institutionalization 3 years earlier.

The treatment plan was for Alexis to be placed in a segregated special class with his full-time aide, two other students, and the special education teacher. His school program was to include a time-out program and a social skills curriculum. Initially, the school was very unhappy with Alexis' performance. He had terrible personal hygiene and engaged in lots of self-stimulation, making faces and acting weird. He was physically and verbally assaultive. He was also frequently tardy to school. Alexis and his aide were soon segregated into their own room, alone, throughout the school day.

According to Clara, the first 6 months after Alexis' return were terrible, primarily for her, as he was her responsibility. She went to his house every morning and forcibly got him up and took him to school (which was less than a few hundred yards from any of the village homes). She supervised his medications, making certain that he took them on the prescribed basis, walked him to school, and spent the day with him alone in a small room until it was time to walk home with him again.

Clara described her program as "shock therapy" using a "hard line." Alexis described Clara as a "hard rock." She used her own form of hard-driving reality therapy with Alexis. She would pound on the desk and cry "cut that out" when he behaved inappropriately. She worked with him one-on-one, using very clear demands and giving him a lot of attention. Clara explained:

The first 6 months being Alexis' aide was very rough. When he first came back to school he was filthy. He wouldn't bathe, wouldn't wipe himself. He smelled so gross no one would get near to him. You couldn't sit by him, he smelled so bad. I would drag him out and make him shower. The principal didn't like that, but I did it anyway. Finally, the principal supported me. I told him smelling bad was not "cool." I would ignore his verbally abusive outbursts (they were terrible). He swore at me, said he was going to beat me up. I came on as really tough and strong. He was obscene, he would describe obscene sexual fantasies. Then he would say, "Aren't you going to take me to the office . . . to the principal?" I told him, "I am your office. I am your principal. I am all you need. You aren't going anywhere."

Initially, Clara felt insecure and unsure of herself, having had no special training for the job and receiving very little support at the school. She felt that the other teachers thought she was mean which, at first, "shook me up a bit." However, a consultant from AYI arrived to observe her during the fall. "He made me feel good, made me feel important, like I was doing a good job." A psychiatrist visiting the school for suicide prevention training also observed her with Alexis and gave her much-needed reinforcement. A consultant from the Department of Education's Division of Special Education, who made quarterly visits to provide the school with technical assistance,



gave Clara materials and suggestions for teaching Alexis personal living skills, social skills, and sex education. These professionals gave Clara very positive feedback and reinforcement in her efforts to manage and support Alexis in his community at critical times during the first semester. With respect to sex education, Clara made the following comments:

I did sexual education with Alexis one-to-one. He could not handle the group situation. Talk about penises and vaginas upset him terribly. He took it as a personal insult. He used to have strange fantasies about a teacher as his girlfriend. He is over that now.

Clara also spent time with Alexis' family, providing them with support and reassurance. By the end of the first semester back in his school and community, Alexis' behavior with his aide had begun to turn around. He literally "cleaned up his act." His personal hygiene improved markedly and his verbal behavior improved also; he engaged much less frequently in sexually explicit, bizarre, and threatening verbalizations. He told Clara, "You don't smell me anymore? No? Good." According to Clara:

Alexis tried to marry me for a long time. It went on for 3 months. I told him I would slap him if he touched me. I told him he could be my good male friend or he could be my enemy male friend. He is now my good male friend. He doesn't fantasize anymore. He doesn't write love/hate poems about ...'s drinking. He can't stand it when a [relative] is drinking. His relative drinks a lot less now ... for Alexis' sake.

School personnel became more confident that Alexis would not attack or kill someone in school. They allowed him to begin going to some other classes with his aide in attendance. By the beginning of the second semester, Alexis was *really* back in school, participating with his peers in non-academic school activities, attending three classes with his age mates without his aide, and functioning well within his family. Clara said:

He got much better. He improved enormously in self-esteem and security. He didn't need to be stroked so much anymore, he had more confidence. He came a very long way. I love my job. I really enjoy what I am doing, the feeling I get from Alexis, seeing him change. He knows now what is good and bad and how to act around people. He used to be rude and demanding. Now he can go to people's homes and act okay. He has helped me, too, helped me to be less domineering, more self-confident.

The night the researchers spent on the school classroom floor, a Friday night, was the night of the first school dance of the season. The dance was held in the gym, complete with strobe lights and rock music from the stereo system. Alexis attended the dance, unsupervised, along with his adolescent peers. Although we did not see him dance with the girls, neither did the other young men. He was socializing and hanging out much as the others, not in any way conspicuous or different.



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By the time of this evaluation, Alexis had been back in his village for just over 1 year. A new school year had started and he was back attending school, integrated into several regular classes. Alexis and his family were interviewed in their home. Alexis was clean, well kempt, and appeared very pleased to have us visit. He had a slight smile and a slightly dry sense of humor. When we greeted him as "Alex" his response was, "Who is Alex? I don't know anyone named Alex," said ingenuously with a very straight face. He then told us several stories from his early life in the village, the time when he had almost drowned but then remembered how to float (many of the village people do not swim) and the time when he was 5 years old and his older sister and uncle fell out of the boat and he had to steer the boat and stop it to save them. He also related a traditional allegory. In this story, two native men are out fishing in their open boat when they are swallowed up by a cave full of white pygmies. These white pygmies were possessed with counting things. "They could count every hair on your head instantly; they knew exactly how many hairs you have. They could count hairs like lightning, but they couldn't count on their fingers to five."

During our visit to his home, Alexis was polite and communicative. He looked directly at us and was very socially appropriate throughout the interview. He reported, "I am doing very well now. The medicine is helping me . . . I don't shake . . . I like to do sports. I like basketball. I do not have bad dreams anymore, now that I am at home."

His mother related, "Alexis is a big help around the house. He talks us up when we are down. We think everything is okay now. Alexis don't have other needs now except for a med check and a medical OK for basketball." Alexis went on, "I want to graduate and then join the Army National Guard. I have a friend in the village who has done this." Alexis spoke as if he were surprising himself at the thought that he would be graduating from high school.

Alexis, his mother, and father all agreed that he was doing very well. His major continuing needs were to have his medication checked and to get a medical okay so that he could join the basketball team at school.

## Evaluation: What Made It Work?

Individualized services and community integration. AYI provided leadership in creating an individualized response as an alternative to long-term institutionalization. It facilitated the design of a program which was developed solely for Alexis, that placed him with support back into his local school and home community, and that helped him learn to work through his problems and issues even though his village was geographically isolated and culturally different from mainstream America.



AYI case coordination. Case coordination was seen by many service providers as being difficult, and perhaps impossible, in a region where the primary services which often reach into the rural villages are school-related services. AYI successfully provided leadership coordination between the state's Division of Mental Health and its Department of Education, effectively reducing the conflict between these agencies. It coordinated meetings, devised strategies, and provided leadership and funds to make the program possible. Case coordination was effective, even when it was done mostly by phone. AYI made it possible to provide mental health services where none were available – in the village. AYI was the vital key: the initiator, the moderator, the mediator, and the coordinator of services to this youth and his family.

Quality of the personnel providing direct care. The aide was clearly a star. She was tremendously important in Alexis' successful readjustment. With considerable natural skill and a little support and assistance from professionals, Clara helped Alexis through a very difficult period of no progress that lasted well over a semester. When asked where she had picked up her skills she said, "My Russian grandmother taught me psychology."

Unconditional care. Alexis' aide's tenacity and determination demonstrated an unrelenting commitment to seeing this youth through whatever he did or said, no matter what. She also developed a strong personal relationship with him based on mutual respect and positive regard.

Consistent structure and firmness. These characteristics were the underpinning of the educational treatment that the aide provided to Alexis, and they eventually turned his behavior around. Clara had to endure an intensive and lengthy extinction phase for Alexis' disturbing behaviors while providing redirection, prompts, physical guidance, and demands for compliance in order to obtain minimal hygiene and behavioral standards.

Family efforts to provide support. Intrafamilial problems were thought to have contributed to Alexis' difficulties. Family members worked to control alcohol-related problems and to reduce stress on Alexis. The family was committed to keep Alexis at home. They also cooperated with and supported Clara in her efforts working with Alexis.

# Barriers To More Effective Services

Insufficient culturally competent services. It is extremely challenging to have people from one culture provide appropriate services to people from a very different lifestyle and background who live in rural, isolated areas with very different world views. The success of the individualized response in this particular case, however,



demonstrates that doing this is not impossible. The difficulties of having Western cultural demands and expectations while serving people of a traditional non-Western culture are demonstrated by this case. For example, school officials were frustrated at parents not taking an active role in their child's education and not making their wants clearly known. Yet doing this was not "natural" to the adults in Alexis' town. In general, his family and many Native Alaskan families found it difficult to be effective advocates for their children in a "Western" sense. Asking questions, seeking information, or questioning decisions or opinions of persons in a position of authority were not culturally supported behaviors. Native Alaskan families do not make demands or ask questions of providers. The only contact Alexis' family had with the distant psychiatric institution was when his grandmother would phone there for information. That was rare, and she was not an effective questioner or petitioner (i.e., she found it hard to follow up on Alexis' request to get someone to assess his medication regime).

Inadequate mental health outreach and service. Mental health outreach and services were extremely limited. The rural isolation and low-population density in this area of Alaska created a significant challenge for service delivery. Alexis' medication was not monitored for more than a year. There was no mental health presence in the village. This problem was compounded by the intense mental health needs elsewhere in the district where the rates of suicide, alcoholism, and domestic violence were disproportionately high. Most of the services in the village were administered by telephone. The mental health outreach person came there only a few times a year. There are many people like Alexis who get shunned, are lonely, and don't know how to act. Often, there is no in-village support for such people. Neither is respite available when a family situation needs "cooling off." Respondents to this study felt that there were people in Alexis' village and in most others who could do mental health outreach if they received training and support. Without more outreach and community-based services, youth are more likely to be sent far away to component programs like group homes and institutions. Having workers in the village would facilitate prevention. At least, the village needed an active advocate and service coordinator.

Insufficient training and support for the aide. The aide had no preservice training and initially received little support at the local school. Visits by a psychiatrist and AYI staff during the first semester provided critically needed support.

Insufficient involvement of parents. When there are very significant cultural differences, effectively involving parents in a core team with Euro-American professionals from the dominant culture becomes a considerable challenge. It takes a long time to find out what Native parents want. Native parents don't litigate for



services, they don't even ask for services. Neither do they become as involved as providers would like to see.

Poor communication and coordination between agencies and family. There was no communication from the psychiatric hospital to the educational system or to Alexis' family about educational progress, psychological progress, or any discharge plan.

Many providers still look to expanding component programs. Many service providers still see the answer to the needs of rural people as making group homes more available or providing money for youth to seek outpatient mental health services in the district clinic, even though they admit that social or behavioral gains that youth make in group settings usually are lost when they return to their homes. Providers seem unable to shake the belief that traditional, Western service models provide answers to the problems of cultural competence, pervasive mental health needs, and serving persons in remote, isolated regions. According to one AYI staff who sang a refrain from Peter, Paul and Mary, "When will we ever learn?"

#### Conclusions

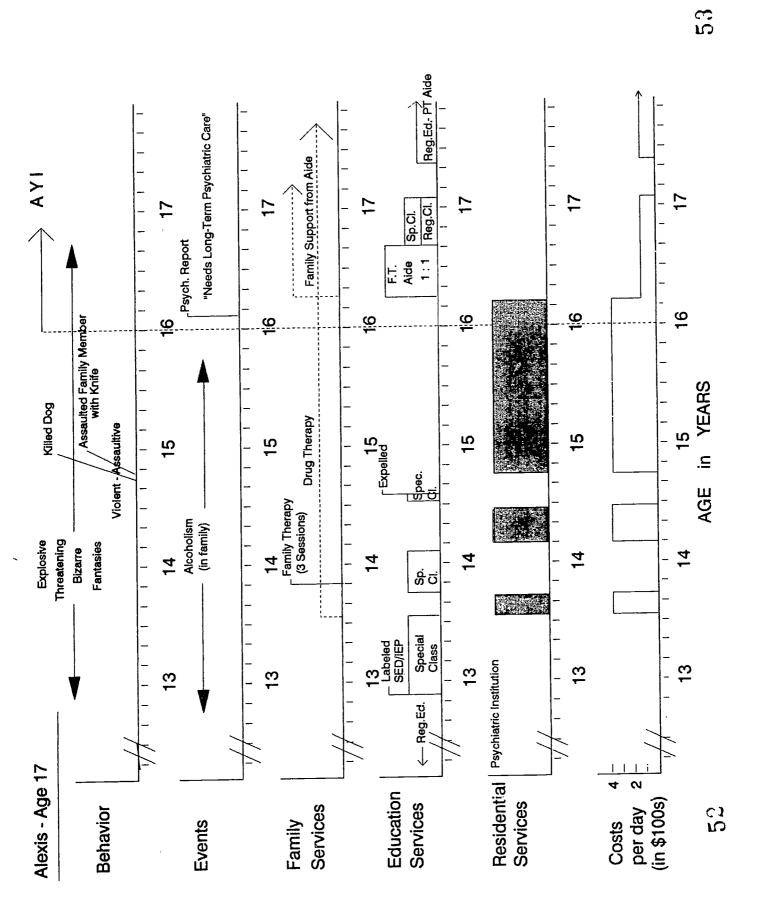
Alexis is a real success story. After three unsuccessful attempts to treat his schizophrenia in an inpatient hospital (and immediately following a psychiatric evaluation which concluded that he would require further long-term inpatient hospitalization due to his mental illness), Alexis was returned to his family and school in his native village with the assistance of AYI core team planning and coordination. An exceptionally strong, full-time aide was recruited from the village and took almost total responsibility for implementing the team plan, providing consistent, firm limits and demands. She received limited consultation and technical assistance from outside professionals and Alexis' family received itinerant mental health services on two occasions within the year.

After one year, following a difficult and challenging first 6 months, Alexis was functioning independently in his school, home, and community. He appeared clean and well kempt and was socially appropriate in his behavior. He attended school dances and other activities unsupervised and was participating in several mainstreamed classes. He no longer engaged in active fantasies or abusive verbal or physical behavior. He was helpful and courteous at home and appropriate in the community. Alexis, his family, his aide, and school and mental health staff all viewed his treatment as highly successful. At the time of the case review, he was planning to participate in basketball at school, to graduate from high school, and to try and join the National Guard. He had improved enormously in self-esteem and in his sense of security.



Alexis' story is one of successfully providing "wraparound" individualized services to a minority youth from a highly different cultural background living in an extremely remote, rural area. The multiaxial timelines on the following page visually represent the major events, behaviors, services, and outcomes related to Alexis' case.

Sources of Information: In addition to reviewing Alexis' records within several agencies, interviews were conducted with Alexis, his mother, his father, the AYI case manager, the AYI local coordinator, the district's special education director, several community mental health agency staff, the local school special educator, the school principal, and Alexis' aide. Interviews took place in the district town and in the youth's home village and school. It should be noted that, due to the transience of personnel in the rural bush region, several members of Alexis' treatment team who were interviewed were new. The principal and special education teacher, as well as the Regional Special Education Director, were new and had never met Alexis.



# Case: Gregory - Another "Classic Case," Non-Classic Response

Gregory also had an abrupt, early adolescent onset of schizophrenia with intense psychotic symptoms (hallucinations, paranoia, and a loss of thought control) a few months after the beginning of his ninth grade in school. Gregory, unlike Alexis, however, was a member of a well-educated, upper middle-class family from the dominant culture. Gregory was a bright student living in a city, taking college preparatory courses in school, and anticipating going to college as his parents and his older siblings had done.

Unlike Alexis' family, which was nonassertive, unquestioning, and accepted without comment or complaint whatever plans or actions were taken by others to intervene with their son, this family was proactive. They sought information, asked questions, and made demands on the service system for action. Gregory's family was unique in that, from the very beginning, they were committed to keeping their son at home and to finding or developing services for him in the mainstream. They were active and highly effective advocates on behalf of their son. Gregory's mother assumed the role of case manager for her son, and performed effectively throughout the family's contact with service providers. Due to her legitimate concerns for safeguarding the privacy of her son, there were few documents of his case retained in agency files.

Because the family was committed to keeping Gregory in the mainstream, a unique aspect of this case was that AYI services were obtained *before* Gregory experienced a series of hospitalizations or failures in the available service systems.

## Background

According to his family's report, Gregory's symptoms appeared virtually overnight 2 months after he entered high school in the ninth grade. He was 14 years old. There was no history of any prior mental health contacts or other problems. Immediately upon the presentation of significant symptomology, Gregory's parents took him to see a physician and then a psychiatrist for treatment. The psychiatrist declared that Gregory was acutely psychotic and began drug therapy and psychotherapy. Gregory remained in treatment with this psychiatrist throughout the next 4 years.

During the next 3 months, Gregory was frequently ill with the side effects from the psychotropic drugs and he had three major psychotic episodes. Gregory's parents were adamant that they did not want him admitted to a psychiatric hospital. However, at the psychiatrist's insistence, Gregory, who was having repeated "illnesses" throughout the fall and winter of his ninth grade, was removed from school. Soon after the onset of Gregory's illness, the psychiatrist began efforts to obtain assistance for Gregory and his family by having Gregory sent outside Alaska for a comprehensive evaluation. This



was followed by further consultation from a child psychiatrist from "outside" to provide support to the parents and help them maintain Gregory at home and in school. The parents felt that the professionals in this situation did not actually know much about maintaining a seriously disturbed youth in his home and school, and that the consultant used this occasion more for gathering information from them than for providing information to them (to his parents and school).

Gregory's parents, despite concerted efforts to involve his school in providing services, were very frustrated and felt they were hitting a brick wall. By spring, Gregory had been out of school for 7 months, with no formal instruction. The school did send work home for Gregory, but provided no instructional assistance. By this time, Gregory's mother felt emotionally and physically exhausted by her futile efforts to obtain meaningful educational services for her son, and it was at this time that the family was able to officially obtain the services of AYI.

# Alaska Youth Initiative: Services and Outcomes

During the spring months, while Gregory's Core Services Team was forming, AYI encouraged the family to obtain respite services. Although Gregory's mother, Mrs. Smith, felt that Gregory was too old for a baby sitter, an older woman was hired to provide respite support to the family. Gregory felt that having this older woman as a companion with whom to play games, take walks, and talk was very helpful and supportive. Nevertheless, since this form of care was seen as age inappropriate by the family, AYI then suggested that the family recruit and pay one of Gregory's friends to take him out to a movie or similar activity on at least a weekly basis. The "paid friend," who was selected by Gregory, worked well for several months until he moved out of town.

Gregory's Core Services Team consisted of the AYI local coordinator, Gregory's mother, and a representative of the school administration. AYI's role was to call meetings, at least quarterly, to make sure that all the major players were in attendance, to help brainstorm solutions to problems, and to provide funding for the implementation of services. During the first year, developing coordination and consensus among team members was exceedingly difficult in the view of Gregory's parents because the school representative often maintained an adversarial position, denying or resisting the provision of services or providing poor services; this person also frequently failed to attend meetings.

Gregory's parents felt that during the first AYI year, AYI staff were not sufficiently available to negotiate for them and their son. Nevertheless, AYI provided funding to continue weekly psychotherapy sessions for Gregory, which included short, 10-minute

family informational meetings, and later, at their request, obtained psychological counseling for family members which they felt was of great assistance. In the meantime, AYI obtained school services from a summer in-home teacher for Gregory. He completed his entire freshman academic work requirements during 2 months of home instruction.

Obtaining satisfactory educational services continued to be a tremendous problem from the family's perspective for the first year and a half after Gregory's "illness" began. Gregory's sophomore educational year began in a segregated classroom with one other youth who had a severe emotional disturbance. This classroom was located in a building far from the high school. An educational plan included 4 hours of academics and 1 hour for swimming and lunch, providing 5.5 hours of out-of-home schooling each day. There also was a graduated instructional plan for decreasing task demands when Gregory began to exhibit thought disturbance. Nevertheless, this experience was extremely unsatisfactory both from Gregory's and from his family's perspectives for reasons that included a lack of effective teaching staff.

As Gregory's mother phrased it, "There was a parade of teachers passing through the classroom and failing miserably." There was, in fact, a succession of substitute teachers with no regular or experienced teacher being available. These substitute teachers, located by the school district, were not adequately trained, prepared, supported, or up to the task. Although there was a written plan identifying how to progressively shorten tasks, provide variety, and redirect Gregory when he began to decompensate (this plan included breaking up tasks, using concrete, short assignments lacking emotional content, helping to focus him verbally, "you are drifting, you are borrowing words"), the instructors were not able to effectively implement these ideas.

Gregory's episodes increased. When he became agitated, he would stay up all night, his mind would race, he would be very confused, and he would be unable to sleep for days. He would take antipsychotics to sleep, but they had dreadful side effects. He would become paranoid. His family sought counseling services, and AYI, through the Core Services Team, authorized them. Mrs. Smith developed diversions to help her son through his periods of agitation, running with him, hiking, and shooting baskets. As the school situation deteriorated during his sophomore year, Gregory's parents kept him home and asked that educational services be provided there. The last 3 months of school during his sophomore year were home-based, although the teacher frequently failed to turn up.

The following comments convey Gregory's opinion that his sophomore year was wasted:

... The first teacher wasn't a teacher; she was a counselor. She did all right for not being a teacher, but she didn't teach. She was trying to teach coping skills,



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and that made it worse. She should have stuck to teaching . . . Then there was this other kid in my class, having major problems. That disrupted everything . . . The second teacher was actually a teacher. At first I wasn't involved at all [other people deciding what was best for him] . . . Then they started including me more. You need to ask the "person" [what they need] . . . also, there was little contact with kids my age; I didn't get to see my friends. You should encourage a person to do things with people his own age. I never was in the high school [that entire year] . . . The next year, kids would ask, "Where were you?" Maybe the separate class should be at the high school.

That summer, the Core Services Team secured a place for Gregory in a summer youth Job Corps program doing forest service work near his community. The crew leader was enlisted as a core team member and was effective in working with Gregory on the job crew. If Gregory couldn't handle the job, he was allowed to return home. He participated with the work crew the entire summer, including one overnight with the group. Gregory enjoyed the experience, stating, "I got along with the kids very well, learned a lot, learned about group living and conflicts."

Learning about parent rights, child rights, and the Individualized Education Plan (IEP) process was exhausting and unsatisfactory according to Mrs. Smith. Functioning as the team leader, she felt that she was not taken seriously and had difficulty getting team members to all the meetings she wanted. This changed somewhat when an AYI worker was assigned who had the time and assertiveness to support her case management efforts. However, this changed even during the summer when she obtained advocacy services from a local agency that was versed in educational law and family rights. Then, according to Mrs. Smith, things began to happen; people began to come to meetings, and her son got a good IEP.

The team agreed to have Gregory return to his local high school for his junior year. This school year saw much more effective treatment planning and, although Gregory had as many problems ("illnesses"), with the assistance of active advocacy and an available, effective AYI coordinator, the core team planned and cooperated enough to provide coordinated and effective services. The school hired an experienced and excellent teacher to be the special educator, a woman who had been Gregory's teacher for the gifted and talented program in his elementary years. "She saw him as a person who happened to have a disability," stated his mother.

Gregory registered for five classes, two mainstream and three one-on-one with the special educator. A plan was developed to handle times when he began to "lose it" at school. In those situations, school demands were systematically reduced, he could leave the mainstream for his special class, and, if he could not remain in school, his teacher came home with him to continue teaching. From Gregory's perspective, "Junior year was a really good program. My friends were there . . . wish I'd had more chance in



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my sophomore year . . . My friends were pretty understanding . . . [they] didn't see me as a freak."

The team began to give some control to Gregory for his own case management. He was encouraged to decide when he could move into a more demanding school situation, and when he should scale back. He was also given control of his psychotropic medications, deciding when he should take them to control his episodes. According to Gregory, "I stopped taking all but lithium by my junior year. I wanted meds without sleepiness. It worked. By my junior year, I knew the symptoms."

Gregory's summer job crew leader, with whom he had an excellent relationship, was hired by his Core Services Team to provide the family with respite and to offer companionship to Gregory. In recognition of Gregory's need for peer socialization experiences, and with his knowledge and agreement, the team hired a peer to act as a friend, 20 hours per week. The peer assignment was to accompany Gregory on community and school outings, to introduce or reintroduce him to a range of groups and activities, to provide feedback about appropriate social skills, and to assist with appropriate expression of anger. Gregory's siblings and other friends also were encouraged to take Gregory out in the community, and his parents felt that this was the most effective source of socialization he received.

Although Gregory felt his paid friend worked out well, he stated, "I don't know why he was paid. We became good friends, went out once a week to ski, to dances, to movies. He helped me get into the mainstream."

That summer, Gregory joined the Job Corps work crew again with the same adult supervisor. This time, the crew worked away from town and Gregory stayed with the crew, living out of town at a forest camp for the entire summer. The crew's job was to lay boardwalk on forest trails. By this time, Gregory was a crew leader and very proud that everyone referred to him as the "Master Planker."

By his senior year, Gregory was integrated into five mainstream classes with one individualized, one-on-one class with the same successful special educator. He also had the availability of a self-contained classroom if and when he needed it. Gregory was in the band and played on an indoor soccer team. By the end of the first semester, he had obtained his driver's license, drove the family car, and received four A's and two B's in his classes.

Gregory graduated from high school in June and became a supervisor of a Job Corps team during that summer, overseeing the team's work in a wilderness setting. At the time this study was conducted, Gregory had enrolled in college on a part-time basis with the plan that he would become a fully matriculated student living on campus by the second semester. He was functioning as his own case manager.



#### Evaluation: What Made It Work?

Interview respondents identified the following key elements of Gregory's treatment needs as being important to the extraordinarily successful outcome of the case:

The commitment to individualized, community-based services. In the midst of professional recommendations and encouragement to consider psychiatric institutionalization, Mrs. Smith, with assistance and support from AYI, remained committed to keeping Gregory with his family and to having him served within his community. Critical individualized services included hiring paid friends, providing summer Job Corps experience and employment, and creating a flexible school program.

Flexible funding. Flexible funding enabled Gregory's family to continue with psychiatric outpatient treatment for their son for 3½ years, a service condition that was basic to the effort to serve Gregory in the community. These funds also supplemented school money, enabling the school to pay the special educator for her individualized services for Gregory. Finally, these funds provided financing for family counseling and paid friends (respite and peer) for Gregory.

Family advocacy and case management. Gregory's family's advocacy for him and their management of his case was seen as one of the most important elements of the successful effort to service Gregory in the community, and eventually in an entire mainstream setting. His mother's strong commitment and tireless work on behalf of her son were tremendously important and effective.

Trusted and respected psychiatric care. The psychiatrist was a continuing point of contact and reassurance for Gregory's parents. Although his role was less important to Gregory ("He was more like a friend"), he continued to provide medication supervision.

Advocacy services. AYI was effective in helping the school to pay attention to parental requests. AYI staff also helped empower the Core Services Team and the mother as team leader.

A competent special education teacher. Although it took a while, the school eventually came up with a competent, knowledgeable, confident special educator to teach and serve as the school case manager for Gregory. According to his mother, the teacher saw Gregory as a person who happened to have a disability, rather than a disabled person. This teacher was able to teach Gregory to use backup procedures whenever there was too much integration into the mainstream at school and he began to feel overwhelmed. She also was able to obtain the cooperation of the school in treatment and educational plans, she coordinated well with his parents, and she assisted Gregory in eventually gaining control over the administration of his own medication.



Peer contact and social integration. Peer contact and social integration was viewed by Gregory as being terribly important in helping him to overcome and to manage his disability. This was achieved by having paid and unpaid peer friends help him with community integration, by successfully working with the Job Corps, and by having as much of his schooling as possible in mainstream classes.

Youth participation and management. Even though Gregory made it clear that he wished people had consulted him more and earlier about his needs, his increasing participation in the decision-making process and his eventual acquisition of the role of case manager were crucial to the success of this intervention.

Interagency case coordination. The planning that eventually took place between the major agencies providing services to Gregory was seen as critically important from the family's point of view. School cooperation with the mental health and parent team members in planning and implementing effective educational services was viewed as absolutely essential. Initially, this was the most difficult piece to put in place.

#### Barriers To More Effective Services

This case study of an individualized and innovative treatment for a youth with acute onset of schizophrenia points out some significant issues that were barriers to the effective implementation of a treatment plan. These issues were as follows:

Ineffective members on the Core Services Team. The team constituted for the first year was inadequate for effective action. No one on the team had enough leverage to promote action or achieve compromise. The parent, as case coordinator, had difficulty dealing with the school and the school's representative to the Core Services Team. While AYI was very pleased that the mother acted as case coordinator and drove the team and the services, Mrs. Smith felt that it was a very difficult role, taking at least one full day a week, and that until she obtained advocacy services she did not have enough clout with the school. The team should have brought in advocacy services sooner as well as a strong AYI coordinator to produce leverage and action.

Difficulty in obtaining appropriate and effective educational services. Finding competent teaching staff and devising a flexible educational plan to take place in the regular school setting took several years. The parents felt that coordination and cooperation between themselves and the school was key. They felt at a disadvantage by not knowing fully their rights (such as in developing an IEP for Gregory) or how to deal effectively with the educational system. It took over a year to develop the information and the support they needed to leverage the educational system into solidly backing the treatment plan and providing appropriate educational services. According to the parents,



A kid's whole life revolves around school. It was so time consuming and exasperating trying to get results and follow through from the school. It took us so long to understand who to contact, when, and what our rights were to get results. It took us two years to master school services.

Disregard of parents' views. Although this was a minor barrier that eventually was resolved, it appeared to the evaluators that progress would have occurred more rapidly if the professionals had spent more time listening to and acting upon the concerns of Gregory's parents.

Disregard of youth participation. Gregory indicated that he did much better when people listened to his point of view about his needs and services. He felt he should have attended most, if not all, of the team meetings. An impressive interview with Gregory indicated that this may have been a minor barrier.

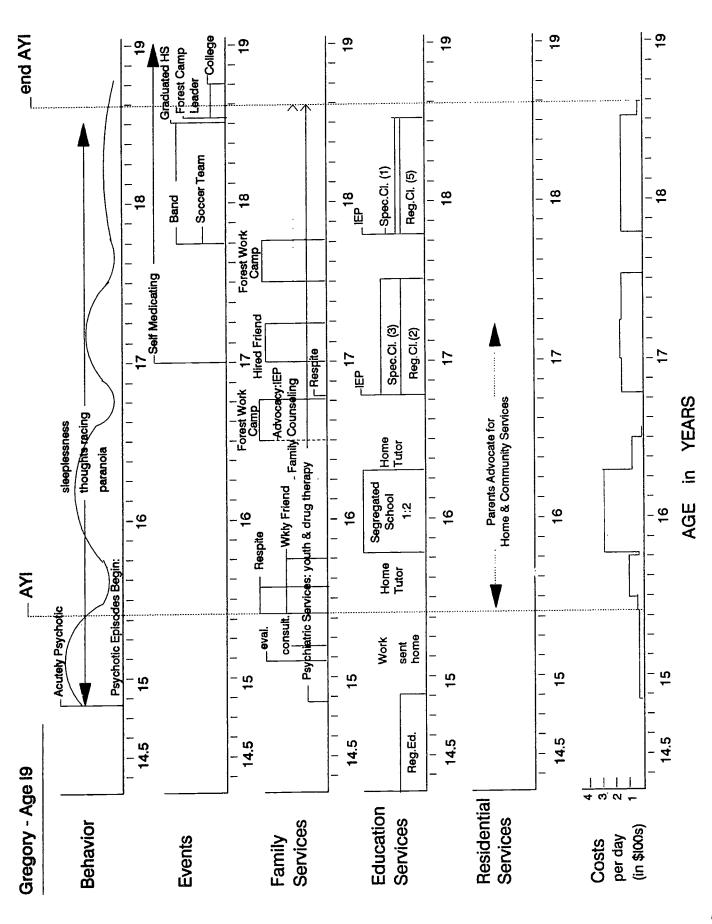
#### Conclusions

Gregory's recovery was seen as enormously successful by all parties, including Gregory. By the time he was interviewed, he had maintained himself in a totally integrated, normalized environment for 12 months, engaging fully in the activities and academics of his school with good success. He was still experiencing symptoms, but managed his symptoms medically and behaviorally. This success was seen by the family to be the result of being able to pursue their own program for Gregory which met his needs, served him in the home and community, treated him like a "regular kid," did not overreact to his episodes, and contained advocacy services which eventually enabled the family to deal constructively with educational issues.

Although coordinating services and putting them satisfactorily into place took time and effort and produced enormous frustration at times, this case study exemplifies a very innovative, highly successful, youth- and family-centered and driven response to a significant psychiatric disability. It illustrates a unique strategy for providing needed services and support to a youth experiencing serious psychotic symptoms, all within his home and community setting without ever resorting to inpatient hospitalization. The major incidents and services in this case are presented on multiaxial timelines on the following page.

Sources of Information: Personal interviews were conducted with the AYI case coordinator, an AYI administrator, the mother, the youth and a community mental health provider. A review of the available records was also completed.





# Case: Tony - A Third Case of Schizophrenia

"The first time I saw Tony he was a ZOMBIE," said the AYI coordinator. "He was lying in a hospital bed in a psychiatric facility and he looked like he was in a vegetative state."

Tony was a regular guy as he went through elementary school and high school, pretty average in lots of ways. His grades in school were okay, "nothing to write home about," and he didn't get into trouble with the police or the principal at school. He attended classes regularly. His parents knew that he would not become a neurosurgeon or a scientist, but they never expected to have any problem with him, and thought that he would grow up to be a responsible adult, probably a mechanic. He played hockey in the youth leagues and always had a bunch of hockey friends that he went around with. There was nothing particularly notable about his family either, except that growing up and living with the same parents is notable in these times. His step-dad and mom worked regularly and supported the family. His step-dad helped with youth hockey. His older brother grew up, left home, and got married. Tony grew up in the same community throughout his childhood and adolescence. Then one day, everything dramatically and suddenly began to change.

Late in the fall of his sophomore year in high school, Tony began to have hallucinations. He would talk to the TV and laugh for no reason. "I hear voices, people are talking to me," he would say. He was terrified, became paranoid, sat staring into space, would not move, could not sleep. He attempted to stay next to his step-dad at all times, crept into his room at night, and slept by his bed on the floor. He was clearly manifesting a psychotic episode according to the psychiatrists to whom he was taken by his parents.

Tony was diagnosed as having a schizophrenic disorder, undifferentiated, chronic with acute exacerbation. In subsequent years, following psychiatric and community treatment, he was diagnosed as having: chronic schizophrenia (by a community psychiatrist); chronic schizophrenia with unspecified mixed substance abuse (during a second psychiatric admission); and organic psychosis and mixed personality disorder with passive/aggressive features (while in a correctional center).

#### Background

As stated above, Tony never was a problem nor had a problem growing up until he became "ill" when he was 16. Tony's parents believed that he had begun to experiment with drugs the previous summer, and had heard him specifically mention LSD. The physicians who saw Tony could not confirm that his illness was due to drugs. He



became rapidly worse, hallucinating, being immobilized at times, and acting paranoid and terrified.

Tony's mother found that there was no help to be had in their community for a strapping young man with Tony's presentation, which she was told was the worst case of schizophrenia anyone had seen. She exhaustively searched out every mental health and medical service available in the community. She was totally frustrated and exhausted by the process: trying to find out "what had happened," "what was wrong," and "what to do." Finally, in despair, his parents had him sent to a closed psychiatric hospital for evaluation and treatment. To accomplish this, however, required obtaining a court order and physically forcing him to go because Tony was unwilling to do so voluntarily. This created even greater trauma for the family and for Tony.

Tony remained in the psychiatric hospital for a month while he was put on psychotropic medications and was evaluated. Following the hospitalization, Tony was returned to his home community, family, and school. His response to his medication, however, was very poor. His bizarre behaviors and paranoia continued. Although the school attempted to provide Tony with a school program by placing him with one other student in a segregated classroom and having a respite worker after school assist his mother, these efforts were unsuccessful. Tony's friends rejected his attempts to regain contact and to obtain support from them.

After a year in the community, which saw him having a series of evaluations from psychiatrists and neurologists and which resulted in no substantive help or clarification of Tony's problem, he had another major psychotic episode which sent him to the emergency room of the local hospital and then back to the psychiatric institute. During this admission, he was placed with adult inpatients. While there, he was discovered indiscriminately taking other patients' medications. He remained there for 5 months, at times in a nearly vegetative state, until he was accepted into the AYI program to receive services and support in his home community. Tony's evaluation of the psychiatric hospitalization was positive: "It was a place to get good drugs... Got someone else's meds and got high... liked it better the second time around... had been there once, was more mature." He was eager to get his hands on anything that would make him "high."

#### Alaska Youth Initiative: Services and Outcomes

Tony was accepted into the AYI program when he was 18. A Core Services Team was put together which included the AYI coordinator, the mental health agency supervisor, two residential services paraprofessional staff members, a psychologist, a local psychiatrist, and Tony. The treatment team met once a week for coordination,

supervision, and planning. Preliminary staff meetings were held first, and then the full Core Services Team meeting with Tony followed. A school representative attended occasionally, as the Department of Education was assisting in funding the plan. The psychiatrist rarely attended. Communication between the team and Tony's parents was ongoing and, according to the parents, they were very involved and highly satisfied with the team's planning and services.

Tony was taken from the psychiatric hospital and placed in a shared-care apartment in his home community with another man who had psychiatric problems. Two male paraprofessional counselors shared the provision of 24-hour supervision and training for the two men.

The residence counselor described Tony as a "basket case" when he arrived from the hospital. He was lethargic, confused, and "walked like a monkey." In the first months, he was generally docile and lethargic, although occasionally he became quite agitated. He would sit between the TV and the stereo, playing heavy metal, both on full blast, to drown out "the voices." Tony was also impulsive, with uncontrolled cravings for immediate gratification from cigarettes, drugs, and alcohol. He paid a man on the street \$5 for one cigarette, was caught "sniffing" coffee grounds, and consumed any pills he could find lying around (including some vitamins he found).

On the street, if Tony saw someone smoking, he would walk up and take the cigarette right out of the other person's mouth. "About got himself and his counselor killed by some GI's," according to his parents. Safety was another issue. Tony would smoke anything; there were fears that, if unsupervised, he would burn the house down through carelessness. One time he fell asleep smoking and set his mattress on fire.

Tony was put on a behavioral program, a point system using chips which were exchanged for privileges. The resident staff's role was to supervise compliance with drug therapy, manage the point system to promote self-care and acquisition of independent home- and community-living skills, oversee transportation and compliance with medical and psychological appointments, assist Tony in looking for jobs, and provide feedback and direction in social skills and interpersonal relations. Tony saw a psychologist for counseling every week and was encouraged to participate in the social program provided for persons with chronic mental disabilities by the local community mental health clinic.

The other client was a violent person. One evening he assaulted Tony. Tony gradually became assaultive to other people. In that year together, "they picked up each other's craziness," according to the psychologist. Tony became more aggressive and violent, both physically and verbally. He intentionally broke a window in a bus. On another occasion, he assaulted his residence counselor.



The counselors took the position that the men needed to learn to accept the natural consequences of their behavior. If they upset the neighbors, they needed to try and square things with them. When Tony or his housemate became especially violent and damaged property, the counselor would file a complaint with the police and have Tony or his roommate taken to jail, booked, and arraigned. A counselor would go with them to jail and stay there, but the message was that they were responsible for their own behavior. This happened on five occasions to Tony during the first 1½ years. Tony also got into trouble in the community, attacking people, breaking property, and wandering into places where he was arrested for trespassing. Tony went to the local jail and was arraigned a total of seven times in his 3 years back in the community for assaults, illegal drug consumption, and trespassing. One time, he remained in jail for 3 weeks.

After 1 year together, following an eviction from their apartment for continuing disturbances, the two men were separated. Tony continued to live with the same counselor one-on-one. He did much better in this situation, his aggressive outbursts and violent behavior subsided to a great degree, and he took more responsibility for himself. His counselor said that he made good progress in behavioral control. He also improved in self-care and self-management. He learned to control himself around other people and not to play the clown or act the fool. He stopped creating aggressive incidents. To the amazement of everyone who knew him, Tony obtained and held a job for 3 days during the summer at a fair. Then he got bored with it and quit. Slowly, he gained more and more personal freedom in the community. With the progress he was making, he became interested in breaking free of the AYI structure and living independently. After 2½ years in "shared care" with the same counselor, he moved for several months into a halfway house for adults with chronic mental disabilities, and then into his own apartment with the support of a 30-hour-a-week street worker to oversee his self-maintenance. A few months later, when Tony reached his 21st birthday, he terminated AYI services.

Tony had continued to live fairly independently in the community for several months at the time of this review, with some supervision through aftercare services and follow-along from the local community mental health center. "Tony is a survivor. He knows where to get help, to get fed if he needs it. He knows where the missions are, the mental health services. He is not antisocial and won't hurt anyone or steal," said his mental health counselor.

#### Evaluation: What Made It Work?

"Tony has done better than expected; his relative improvement has been tremendous!" said his psychologist. "He is living independently now with some supervision from



adult mental health services. We expected him to OD, or be hit by a car, or set himself on fire. But he has survived for 4 years in the community, the last year pretty much on his own."

Upon admission to AYI, Tony was seen as a person with chronic schizophrenia who would spend most of his life in an institutional setting with no ability to manage for himself even the simplest skills of daily living. Tony's success is that he is able to survive on the street now, and that is what he wants. He isn't a zombie anymore and is somewhat independent. He learned to cook meals, maintain marginal personal hygiene, and understands something about handling money. He was given the opportunity and support he needed to adjust to living in the community where he wanted to be. He is no longer a danger to other people, he does not steal or damage property, or assault people. He knows his way around the community, and the community knows him.

It is also clear that Tony will never be "normal" in the usual sense. Although his parents continually got the message during his hospitalization that Tony would get well, both parents and providers came to realize that he will always have a disability. "He'll never do normal things. His apartment is a mess. He wouldn't clean it up in 40 years," says his mother. His adjustment is marginal and he will always need followalong services from mental health providers. But he is where he wants to be, living in his own apartment in the community, with the need for public assistance and daily support services.

The successes that were achieved were viewed by the evaluators to be a function of the following features of the services AYI provided:

Teamwork, coordination, and cooperation. Tony's Core Services Team met often and maintained a high degree of communication, coordination, and consensus. The team and supervisors provided a great deal of support and advice to providers on an ongoing basis. Direct providers were given an important voice in meetings.

Family support. The providers stated that in every case, family is critical to success. In Tony's case, the family was supportive of team efforts and of Tony. They felt that the AYI team made every effort to communicate with them and to keep them informed, and that their son benefitted enormously from the community services that were provided.

Excellent direct care staff. Although paraprofessionals, the residential counselors who provided direct care formed strong bonds with Tony. They were able to implement a structured, contingent program to teach responsibility and life skills while maintaining a strong relationship with their client. One counselor was the major service provider for Tony continuously for 2½ years. Tony liked his residence



counselors a lot. "[They were] good guys. [One] would be a good husband and is a good cook. The other is like a rock singer."

Structured program with contingencies. A paraprofessional staff person said:

Tony and others taken on by AYI are very disturbed people. They are tougher cases than most providers have ever had to deal with. The usual modus operandi, "love and positive attention," is too soft and doesn't work. [At the same time], psychiatric care, prescribing and changing drugs without team involvement, no meaningful client contact and no interest in data-based information for making the changes [is inadequate for client rehabilitation]. The point system taught quantitative values, daily and community living skills, and it reinforced socially appropriate behavior.

Individualized and one-to-one programming. AYI flexible funding and programming allowed intensive one-to-one services to be provided which, in turn, allowed the individual to prepare for group or independent living in the community. AYI's approach gave Tony the opportunity to get adequate support so that he could learn to live outside of an institution.

## Barriers To More Effective Services

People interviewed during this study were able to identify issues that impeded the provision of effective services in the community for an individual with severe adjustment problems like Tony. These issues included:

Group residential care. Placing two individuals with disabilities in shared care where they vied for attention and adopted each other's most inappropriate behaviors was an impediment to helping each of them adjust to their community and acquire appropriate living skills. Placing two such individuals together was a decision driven by financial considerations. Nevertheless, many of those interviewed felt that adjustment and rehabilitation would have been faster and progressed further if Tony had been given one-on-one services from the beginning. "Two in shared care picked up each other's craziness... lived together to reduce expenses – poor choice."

Lack of community-based help for youth manifesting psychosis. Initially, Tony's parents were distressed at the lack of services available in the community and the difficulty in getting a diagnosis or adequate help. They also were frustrated by legal barriers encountered in having Tony hospitalized. Later, they had problems with his being on the street, fearing for his safety. "We would like to have him in a more structured program, but he refuses. He needs more time in AYI, but there is no way to force him."



Lack of community education about psychiatric disabilities. The lack of community information, education, and preparation for serving individuals with mental disabilities was seen as a barrier to providing care to Tony. There is a great need for more community education. Tony's parents were "amazed at how scared people are of Tony."

Lack of short-term crisis stabilization. There is a need for short-term crisis residential facilities with the potential for restraint to stabilize clients experiencing severe agitation or anger and who are in temporary crisis. In Tony's program, after the initial 2 years, the court and corrections department cooperated to provide short-term back-up for Tony when needed.

#### Conclusions

Tony, like Alexis and Gregory, had a sudden onset of schizophrenia during his adolescence, following what appeared to be a relatively normal and uneventful childhood and youth. Whether or not his psychosis was precipitated by experimentation with drugs was never ascertained. He was left, however, with indiscriminate cravings for substances of all kinds and a drive for immediate gratification. After an initial hospitalization, followed by a year during which his family sought assistance in the community, Tony was hospitalized for what might have become an indefinite period with chronic schizophrenia.

Although community treatment through AYI services cannot be said to have cured Tony, Tony was able to maintain himself in the community, learning self-care and some degree of self-control. He also learned where he could obtain services and support. After several years with one counselor, a few months living in an adult halfway house, and a few months with partial supervision living in his own apartment, he was now living in his own apartment independently.

Still, Tony's adjustment was marginal. At the time of this study, he wasn't working and he will undoubtedly continue to require follow-along mental health services indefinitely. However, he no longer presented a danger to others in the community. Although his family continued to worry about his personal safety, he was where he wanted to be, living on his own. Through the intercession of AYI and the provision of structured residential services in a training apartment with continuity of staff, Tony had been able to live in an open community setting for 2½ years by the time these interviews were conducted. AYI's services provided Tony with an alternative to indefinite or repeated institutionalization.

The multiaxial timelines on the next page show the major events, services, and behavioral history in Tony's life. Tony, like the other two youth experiencing

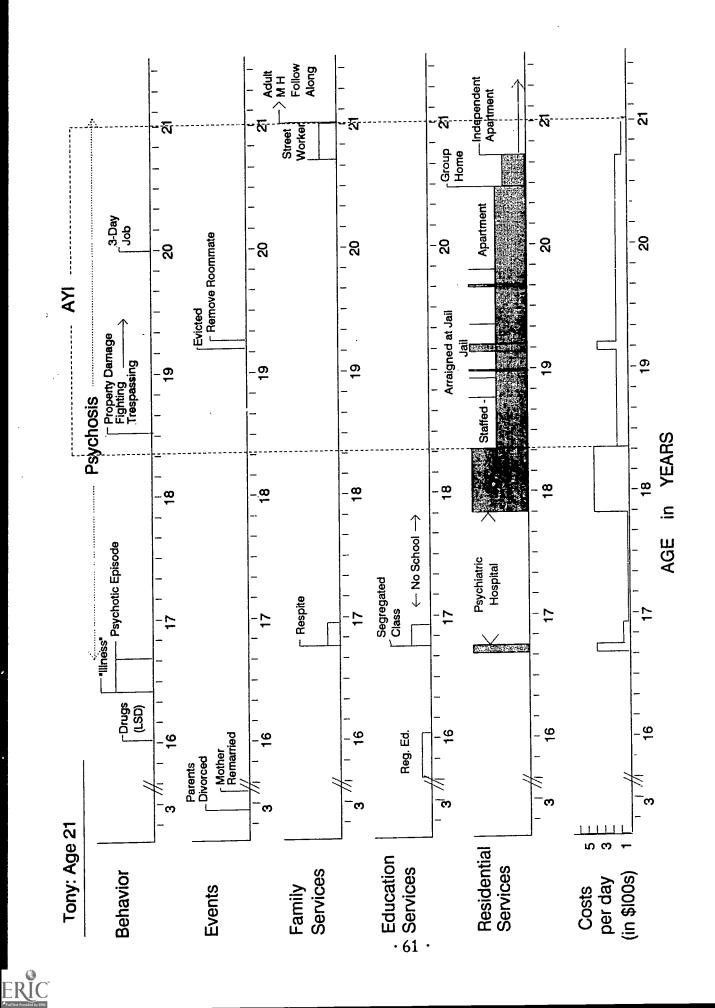


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adolescent onset schizophrenia, received individualized services from AYI designed to maintain him in his home community with support so that he could live as independently as possible. Although he will always need some supervision, he was, in fact, living quite independently to the surprise of many of his human service providers.

Sources of Information: Information for this study was developed from a review of case records and from personal interviews with Tony, Tony's parents, the AYI coordinator, two residential counselors, and Tony's psychologist.

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# **CHAPTER 4**

# The Challenge of Cultural Competence: A Case Study of a Native Alaskan Youth

Without AYI Gloria would be in an institution. As a result of this experience, I will never send another child to the psychiatric hospital unless blatantly psychotic. They would just send her back with bottles of meds and a diagnosis... My only reservation is that so many thousands of dollars were spent on the child and nothing was spent on the mother. What if we had spent something on the mother?

These remarks were made by Gloria's child welfare caseworker approximately one year after Gloria began receiving services through AYI. In addition to illustrating the remarkable progress made during that year, this case highlights some of the complex parental and cultural issues involved in providing services to children with severe behavioral and emotional problems. Under what conditions should services be delivered outside the community of tie, particularly when the "outside services" have to be delivered within a different culture? If outside services end up being delivered within another culture, what relationship should exist with the natural family? These are some of the more prominent issues that characterize this case.

# Background

Gloria is a Native Alaskan who was born in the late 1970s in a small village where she lived with her mother and several siblings. Life in the village was a constant struggle, at least for the natives who constituted over 90% of the population. In general, the predominant issues were comparable to those experienced by most of the natives in Alexis' village. The absence of jobs placed about 90% of the families on public assistance; a housing shortage forced two and three families to live together in small, single-family houses located side by side on small plots of land; and any substantial need for service required a time-consuming ferry ride (several days) or a costly commuter flight (over \$100) to a more populated area.

All of the teachers and all but a few of the aides in the school were non-Natives who tended to leave the village during the periodic breaks in the school schedule. As in



Alexis' village, this racial and financial separation was reinforced through the television programs watched in every home depicting the "majority" society, created a "we-they" mentality that produced varying amounts of resentment among the natives.

Little is known about Gloria's father except that he was an alcoholic whose only contact with his daughter was a brief visit when she was 11. Gloria's mother had serious drug and alcohol problems throughout the time that Gloria lived in the village and probably was a significant consumer during her pregnancy. Gloria's mother attributed her own problems to a chaotic childhood which included considerable neglect from her alcoholic mother and substantial, long-term sexual abuse. The severity of her struggle with substance abuse is reflected in her recollection that Gloria, at age 5, had to call 911 to summon police when she overdosed on drugs. Her attempt to cope with the problem is reflected in her voluntary participation in a 30-day in-patient alcohol treatment program when Gloria was 10, and again when she was 11.

Gloria's early childhood was characterized by a lack of supervision and discipline. At a young age, she began stealing from her family, friends, the school, and the village store. By age 8, she was not allowed to go into the store without supervision and she was referred to in the village as the "troublemaker." Her mother was frustrated with her behavior, but found it difficult to cope and to provide the consistent discipline that might have stopped the stealing. In fact, she described instances when she would defend Gloria because so many people were against her and treated her negatively. She does not recall ever spanking her for lying or stealing, and now believes that she should have treated it as a more serious problem.

By age 9, because of her stealing and unsupervised wandering around the village at all hours of the day and night, the state child welfare agency began providing protective supervision for Gloria. In response to a neglect report, she was removed from her village and placed in voluntary foster care in the closest non-Native community (a day's distance away) while parent training services were provided to her mother. Over the next several months, Gloria was transferred back and forth between her mother and her foster parent as the child welfare agency attempted to achieve family reunification. Shortly after she was 10, Gloria reported to her teacher in the village that she had been sexually abused by an uncle.

According to Gloria's mother, the day she learned of the sexual abuse was the worst day of her life. After crying for hours, she reluctantly told her father and another brother. Family members were shocked that Gloria would divulge such information to a teacher and, when the uncle eventually received a 10-year prison sentence for the offense, Gloria and her mother became the black sheep of the family. To the time of this study, Gloria's grandfather rarely spoke to either of them. Although Gloria's mother said she fully understood the trauma of sexual abuse, her opinion at the time

of this study was that she and Gloria would have been better off if the report had never been made.

Gloria's mother states that she was notified of the sexual abuse by telephone and that the next day a social worker came and took Gloria out of the village and placed her in another foster home. Although it was suspected that Gloria's sister had also been abused, the social workers were never able to obtain any confirmation. The social worker for the Native Association said she felt that Gloria's sister had been sexually abused but that "fortunately for her" she was too scared to talk.

During Gloria's first 20 months in state custody (ages 9-10.8), attempts were made to provide outpatient counseling for Gloria and her family. During what the professionals described as a very "episodic period," sessions were held with a social worker, a psychiatric nurse, and a counselor in varying combinations and frequencies. At the end of this time, it was concluded that the outpatient counseling had not met with positive results and it was recommended that a structured residential, long-term setting was needed to thwart Gloria's inappropriate sexual impulses and to provide a controlled environment that would allow Gloria to develop internal self-controls.

During this same time period, school officials were also recommending long-term residential treatment. In general, her performance was far from age appropriate. By the fourth grade, she had been classified as learning disabled. In the fifth grade, as a result of poor social skills, increasingly disruptive behavior, stealing, and a need for individual attention, the classification was changed to seriously emotionally disturbed and she was placed in a self-contained special education class.

At a mental health clinic in her foster care community, a psychological evaluation revealed that Gloria was of low average intelligence and that two important psychological features characterized her maladjustment. One was a lack of interest in other people, and the other was a lack of a real sense of self. Both of these characteristics were attributed to her inability to learn to be accountable to others due to a general lack of discipline during childhood. It was felt that because she had not developed a wholesome relationship with others, she had become generally unresponsive to social praise or internal self-control as a means of direction. It was recommended that the state maintain custody for another 2 years and that she be placed in a residential treatment program.

At age 10.7, Gloria was returned to her mother who had moved to the foster care community from her Native village. Her mother had completed two 6-week sessions of a parenting class, had agreed to participate in alcohol and vocational rehabilitation counseling, and had agreed to homemaker services to assist her in the management of her home. In retrospect, she said she resented the need to attend the parenting classes and she was offended by the homemaker services.



After 1 month with her mother, Gloria was caught stealing from the neighbors. It was also discovered that she had been involved in sexually fondling other children in the neighborhood and that a teenage female and a friend of the family had been molesting her periodically for the previous 2 months. As a result, Gloria was placed for further evaluation in a private psychiatric hospital located a considerable distance from her village and her foster care community.

Gloria spent 6 weeks in the psychiatric hospital where she was described as being extremely oppositional, defiant, and omnipotent. She needed consistent structure, and, at times, complete seclusion to help extinguish her defiant attitude. Her diagnosis was conduct disorder, undifferentiated type, and dysthymia. At the end of her stay, her psychiatrist felt that she had worked through her own sexual abuse and understood that she was abusing others because of her feelings of anger and resentment. He recommended a 6-12 month stay in a group home followed by a long-term stay in a specialized foster home. The final recommendation from the hospital, however, was that she be placed in a long-term residential program to be followed by specialized foster care. According to this report:

It is during this period that parental visitations and the degree of [her mother's] competency to care for her child can be fully evaluated. It is unlikely that this plan will take less than 18 months... [She] needs to feel secure in her surroundings to extinguish the negative behavior she has exhibited such as lying, stealing, and sexually inappropriately touching children. Her supervision is an important aspect because she has been sexually abused when in her parents' supervision. [She] needs protection from physical harm and the ongoing supervision that will prevent sexual abuse.

Gloria was then returned to her mother for approximately 1 month while her caseworker sought the next placement. At age 11, Gloria was transferred to a residential treatment home near the psychiatric hospital. She ran away several times to the downtown area with other troubled youths. On one occasion, she was discovered in a nightgown in one of the bars soliciting drinks for kisses. In retrospect, Gloria said she liked the treatment home, "I had a lot of friends there. They cried with me, and they ran with me."

Over the next several months, Gloria went back and forth from the treatment center to various psychiatric hospitals as her caseworker pursued an out-of-state residential placement. School officials in her foster care community had made it clear that they would no longer tolerate her acting-out behavior and that the only way she could receive an appropriate education was through an out-of-state placement. While in the hospital for her third evaluation, she was diagnosed as a borderline personality disorder.

Since all in-state services had by now been exhausted, an application was made to the Alaska Youth Initiative.



## Alaska Youth Initiative: Services and Outcomes

At age 11.4, Gloria was accepted into AYI and a Core Services Team was assembled to plan and implement individualized care. The ream initially consisted of the AYI director, the AYI Local Coordinator, the child welfare caseworker who had been working with the family since state custody had been initiated, and a school administrator from the foster care community where she had been receiving educational services since second grade. Foster parents, special education teachers, and relevant child-care staff joined the team as they became part of the service plan.

During the 3 months it took to plan her program and to hire specialized foster parents, Gloria was returned to the residential treatment home she had been placed in on previous occasions. However, the school in that community was loath to take Gloria back. They considered her too aggressive and too dangerous to the other pupils and the teachers. According to the special education teachers:

No one believed she could "make it." She'd as soon hit you as hug you. After hurting someone, she'd have no remorse. I'd say, "You hit her in the mouth?!" and she'd respond, "So?"

The Core Services Team prevailed over the school by threatening a legal due-process hearing, by enlisting the support of the special education teacher through appeals to her professionalism, and by providing aides to "guard" Gloria to prevent her from harming others. She began by spending a half day in a special education class and a half day in a mainstream class with her aide in the local public school. Nevertheless, on one occasion she still managed to assault a police officer who was called in to protect the teacher and, according to the teacher, the "guards" quit as they were too frightened to continue.

The Core Services Team then hired an experienced aide with excellent behavior management skills to replace the "guards" and to work with the teachers. Nevertheless, Gloria was no longer allowed to attend regular classes and she received only a half day in the special education classroom for the remainder of the school term. The special education teacher was the only person in the school who would agree to work with Gloria, even under threat of due process. For the remainder of the term, Gloria's teacher worked closely with the new aide, learning and implementing a point-based behavior management system.

Gloria's adjustment to the unlocked group home was equally problematic. The other five residents were described as some of the "toughest boys in the system." It was unclear who influenced whom. Nevertheless, Gloria ran away on numerous occasions, usually with one or more of the boys, to a local teenage homeless hangout in town. There was also at least one sexual encounter with one of the boys in the group home; many more were suspected.



Gloria was 11½ when she moved into the AYI specialized foster home. The Core Services Team had hired a couple from out of state to serve as foster parents. The foster family also included a daughter who was 5 years older than Gloria. Unfortunately, this placement was much like the others and lasted less that 2 months. In addition to her generalized noncompliance and defiance, Gloria ran away on numerous occasions. When the AWOL's reached a frequency of six in 2 days, one of which included the foster parents' daughter, this placement was terminated and Gloria was returned to a psychiatric hospital.

In retrospect, members of the AYI Core Services Team attributed the placement failure to limitations in skills and commitment on the part of the foster parents and limitations in training and support on the part of AYI. For example, the foster parents were either unable or unwilling to implement a reinforcement system for Gloria and when Gloria ran away they did not feel that they should be responsible to find her and bring her back home. On the other hand, AYI did not anticipate the need for extensive training of the foster parents and was not prepared to provide it.

After a short stay in one psychiatric hospital, Gloria was transferred to a second one where the director of the children's unit agreed to retain her until the Core Services Team could assemble a community-based alternative. This provided a critical "backup" for AYI and reflected a working relationship with a psychiatric hospital that had not previously existed. At this point, the Core Services Team chose not to return Gloria to either a group home or to specialized foster care, but rather to implement services somewhere in between. In effect, they created a group home just for Gloria.

The residential part of the services was referred to as a shared-care, transition home. Shared-care involved renting a two-bedroom apartment and staffing it with enough people (approximately five) so that at least one well-trained person was on duty at all times. In addition, several "experts" were brought in from "outside" Alaska to provide intensive training and consultation. One of these persons lived in the home for 3 weeks.

The treatment modality in the shared-care home involved a comprehensive behavior management system. Although this was an expensive placement, it was no more expensive than a psychiatric hospital and the Core Services Team felt that it might be a cost-effective entree into a second specialized foster home.

The shared-care experience was somewhat rocky at first, both for Gloria and for the staff. She ran away almost immediately, but was caught and returned within 20 minutes. She tried to run again, but was physically prevented from doing so by staff. Soon, the point program which provided many activities and positive outcomes had time to "kick in." As part of her behavioral program, Gloria received a lot of positive attention from staff and an enriched schedule of activities, many of her own choosing.



It took some time for Gloria to realize that AYI was a program from which she could not run, and it took time for the staff to develop consistency across shifts. After 3 months, Gloria's behavior stabilized and she was ready to reenter specialized foster care.

Another advantage of the shared-care placement was that it provided a training/testing ground for specialized foster parents. Unbeknownst to Gloria, the person who was to eventually become her foster mother was one of the shift workers in the shared-care program. Having a shift worker become a foster parent also provided a more gradual transition to normalization and facilitated the generalization of Gloria's behavioral change.

Gloria's initial response to specialized foster care was similar to her initial response to previous placements. Her increased acting out was highlighted by a couple of brief runaways. On two occasions, the foster father had to use prolonged, physical restraint to prevent physical assault or running away; once she was restrained for about 1 hour after she slapped her foster mother, and once for about 1½ hours to prevent her from hitting others. These incidents, however, declined and, over the next several months, the foster parents were able to remove much of the behavior management system.

As Gloria moved from the shared-care apartment into her specialized foster home, the new school term began and Gloria entered seventh grade. Her special education teacher had been receiving much support from the Core Services Team as well as direct instruction on how to "catch" Gloria being good and how to use point systems and positive reinforcement. By early in the seventh grade, Gloria felt that everything had turned around. She liked school, worked hard, and was beginning to take responsibility. By the second semester, she was spending most of her time in the regular classroom where she was responding well and she was participating in cheerleading and in a Native Alaskan dance group. According to her teacher, she was acting like and was indistinguishable from the other adolescent girls in the school. By the end of the term, Gloria was no longer on the point card, and she was on the honor roll.

Similar progress was made at home. The foster family received respite by having Gloria spend time with another family which included teenage children. She joined them for special activities and weekends, during which time she was on "respite" from her point program. She never abused that privilege.

At the time this study was being conducted, Gloria was attending a week-long co-ed residential swim camp on a total mainstream basis. She was not on any behavior management program and no one at the camp knew anything about her past behavioral problems.

### Evaluation: What Made It Work?

The progress that Gloria had made by the time of this study was expressed by providers in many ways: "She now has a sense of humor," "She can talk things out," "She no longer wants to visit the seedy bars and hotels," "She doesn't want to return to her village, but rather wants her mom to visit her here," "She loves school," and "She's conscious and proud of her appearance."

As a caseworker who had known her over the years succinctly put it:

Gloria's story is an incredible success. Without AYI intervention, she would have had many more placement failures and eventual institutionalization. To see the transformation from an angry, vulgar, aggressive tramp to a pleasant, regular teen is marvelous. I do not worry about her molesting other youngsters anymore.

When those who participated in the delivery of the AYI services were asked what made the difference, the most common responses were:

- The interagency effort through the core planning and treatment team.
- The unconditional commitment to Gloria.
- The skill, compassion, and commitment of the AYI Local Coordinator, and the specialized foster parents.
- The home-school coordination, technical assistance, and support for the special education teacher.

Other characteristics that were identified, although they were mentioned less frequently, were:

- A teacher who was willing to be flexible and "hang in," particularly after she was given more support from the team and the home.
- The use of a psychiatric hospital as a safe place to maintain Gloria after her removal from the first specialized foster home while the shared-care program was being established.
- The use of shared-care to stabilize Gloria in the community prior to her transition into the second specialized foster home.
- The structured behavior management program at school, in the shareu-care home, and in the second foster home.
- The flexible use of the behavior management program by the second foster parents that allowed Gloria to be mainstreamed into the summer swim camp.



- Decent wages and respite for the foster parents. Sixteen hours of respite were provided each week during the school year, and 24 hours each week during the summer. The wage for the foster parents was approximately \$85 a day.
- A very "normalized" respite family which included Gloria in many social and recreational activities with their own children.
- The use of controlled physical restraint by the foster father to prevent Gloria from assaulting others and from running away.

## Barriers To More Effective Services

In general, there was considerable inconsistency in identifying barriers in this case. While most of the participants agreed that additional "within-family" resources might have prevented the first placement, there was less agreement with AYI's decision to serve Gloria outside of her village and apart from her family. Thus, in this case, it is less clear what would have made it work better. Some of the major areas of controversy will be presented and discussed, beginning with excerpts from a very emotional interview with Gloria's mother concerning her feelings about several aspects of Gloria's care.

## With respect to the foster care:

At first I was excited. I thought it would help. But she had to live with them, I didn't. I felt like I was low man on the totem pole. Good or bad, I was told nothing except that the program would be good for her. My input was never a big thing. I realize I had problems and did not always cooperate, but I am her mother.

## With respect to Gloria's sexual abuse:

I take care of my father. He's 90 years old. He speaks our native language. I understand the language, but can't speak it very well. He will never understand what happened to Gloria. Sexual abuse is something our people don't talk about. I'm surprised so many people in town know it happened. I talk to God, He won't tell others. Gloria, too, should talk about her abuse, but to a familiar face. She was hurt. We didn't know how much. Now she is encouraged not to talk. Survivors are not encouraged to talk. There are a lot of caring people, but when you need them they're hard to find. We were singled out and treated badly by our family. They blamed her. Wrong things were said to her. Even her nieces and her sister said wrong things to her. At that time, I felt like a snowball and everything under me was melting away. I drank too much and I ate to much. I weighed 395 pounds.



### With respect to AYI:

I'd like to feel like I'm her mother. I'd like to see her more. When I do go, it's a supervised visit. There has to be advance warning. They don't pay for nothing. I have to find a place to stay. They want me to come to a meeting, but I can't just jump on a plane and go. I'd like them to call me more. Call me when she's having a bad day. I want to know her progress, both good and bad. I want to feel like I'm her mother. I want to hold her. Not just to say I love you but, just to hold her. My mom never held me. Gloria and her sister need to be held, to hug and cry with each other. Otherwise, it doesn't make any sense to me.

Gloria's current foster parents provided a different perspective. They were concerned that whenever Gloria spent time with her mother, her behavior and attitudes deteriorated and she lost much of the hard-fought gains she had made. Since spontaneous, uncontrolled visits seemed to be the most problematic, they confirmed that they required advance notification. They also stated that there had been several occasions when Gloria's mother was in town and showed no interest in Gloria. In general, their objective was to help Gloria make the most normal adjustment possible by the time she reached 18. At that point, they feel she will be in the best position to decide whether or not she wants to return to her mother in the village.

A third perspective was provided by officials within the Tribal Association. They felt that this case illustrated a major flaw in the service delivery system: Certain services break up the family and the community. They acknowledged that terrible things can and did happen to children in that village, but they believed that removing a child from the family is wrong. Some of their suggestions were:

Bring services to the village. Teach us how to do our own AYI. If a child needs to be removed from the village [and some do], the whole family should go with that child. It makes no sense to take a child away, to try to fix him or her, and then to send the child back to the family where nothing has changed. Take family "X" [an AYI family other than Gloria's]. They still haven't learned to love their children, and now the younger brothers are starting to have problems. Also, look at the money being spent to take the child away. It's enough to fix the whole family. The only way the child will get well is through the family. You need to get the love between the child and the parents. You need to get everything out in the open and not to let families hide everything. You can buy care [foster parents] but you can't buy love. Before long, the foster parents are gone. The parents are never gone . . . There is a lot of abuse in this village, but you don't fix it by taking the children out one at a time. You fix the families. And, once the families see what happens to one family, they will all want it.

The position taken by Gloria's foster parents was understandable. If she could continue to make progress for a few more years she might have better skills and a better attitude



toward herself that would enable her to cope with the problems of her past. Nevertheless, the concerns raised by Gloria's mother and the representatives of the Tribal Association also were important and raised critical questions, particularly with the way services were delivered in the past. What village-based resources would have been necessary to help Gloria's mother cope with her drug and alcohol problems during the prenatal period? Gloria's mother maintained that she knew more about raising children than about coping with the abuse and neglect of her own childhood. Enabling her to work through some of those issues might have facilitated her efforts to become a more effective parent.

At the point where the child welfare agency became involved, the decision was made to place the child outside of the village. Partially, this was because there were no certifiable foster homes in the village due to the crowded conditions. Placement out the village happened in response to Gloria's stealing and wandering as well as in response to the substantiation of the sexual abuse. In general, child welfare agencies are more prepared to separate, remove, and serve children elsewhere than they are to support and promote what already is there. While placements are made to "protect the child," one has to wonder what the outcome in this and other cases would have been if the same amount of money had been spent wrapping services around the family. For example, it was unclear that any meaningful services were provided either to Gloria or to her family prior to the numerous times she was removed from the village. Neither were meaningful services provided during those periods when she was returned.

At the point when AYI became involved, the decision was to serve Gloria through specialized foster care rather than to return her to her village and serve the entire family. Given the magnitude of her behavioral problems at that point in time, and the pressures to send her out of state, the decision appeared to have been a sound one. However, it might have been beneficial to provide more services to the mother and to involve her more actively in the treatment process. She has a point when she says that the state pays for everyone except the parent to attend the meetings of the Core Services Team.

Finally, in terms of the more preventive, family promotion concerns of the Tribal Association, it is recommended that an AYI-type program be developed and administered within the village. If culturally relevant, early intervention, wraparound services could be administered within the village, it could approximate a more ideal service delivery system.

#### Conclusions

Gloria spent her early childhood growing up in a single parent family where there was little stability and supervision. Although Gloria's mother loved her children, she was



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too overwhelmed with her own problems to provide them with adequate parenting. Gloria was removed from her home and village, first because her behavior was unmanageable, and then because she had been sexually abused.

As Gleria's situation became increasingly challenging, she was moved into more restrictive placements in the child welfare system. By the time she entered AYI, she had failed in more than 11 different placements and there was considerable pressure to send her to a residential treatment center out of state.

While in AYI, Gloria made remarkable progress. After "blowing through" one specialized foster home and a brief stay in a psychiatric hospital, she was stabilized in the community in a shared-care home and then transferred to the home of one of the staff where she gradually reentered the mainstream. At the time of this study, Gloria was successfully participating in a summer camp where everyone was unaware of her past.

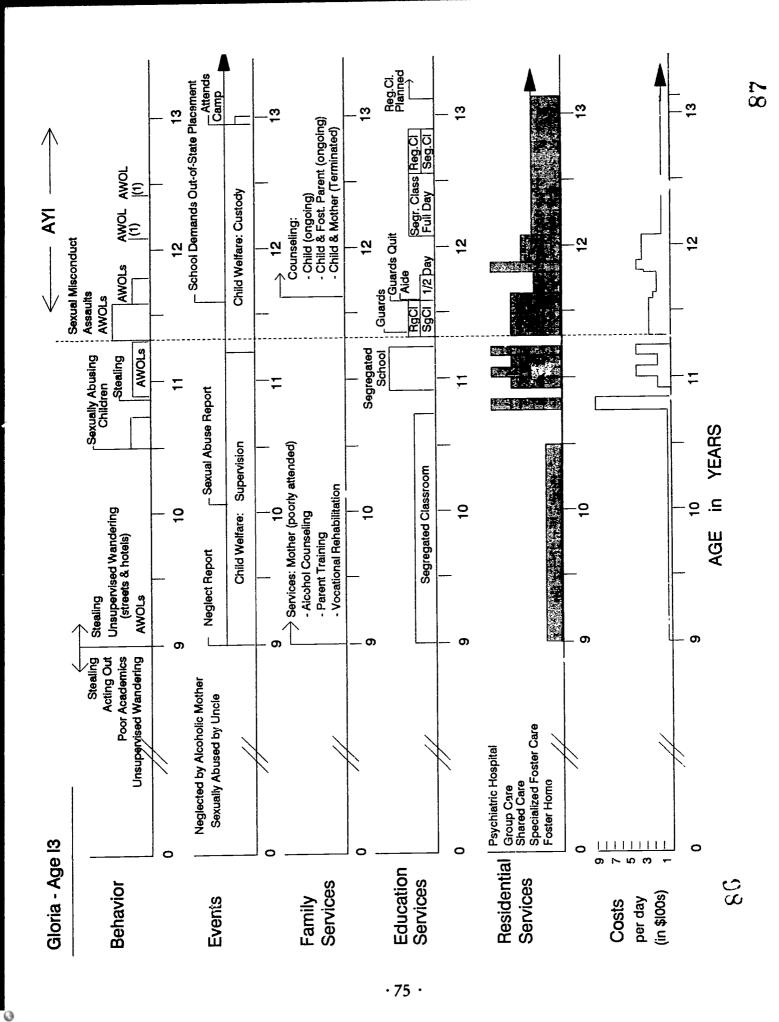
While the case was a remarkable success, it raised significant cultural issues. Gloria's mother and members of the tribal council acknowledged the progress that Gloria made, but they were resentful that it was done outside of their culture and with only a minimal involvement of her family. They believe that an equal amount of progress would have been made if AYI had brought all its resources to the village and worked with Gloria and her family in their natural environment. Most of the service providers who worked on this case disagreed.

There were two important areas in which where there was much less disagreement. One is that much of the failure that Gloria experienced in the child welfare system could have been prevented if AYI-type services had been brought to the village at the point where Gloria was first being considered for an out-of-village placement. The second was that if villages like Gloria's were given the means to administer their own AYI program, they could prevent future Glorias, and they would be doing this with a much greater degree of cultural competence.

On the following page is a multiaxial timeline for Gloria which provides a visual display of relevant behaviors, events, and services provided together with an estimate of the cost of these services.

Sources of Information: Information for this case was obtained by reviewing case records and by conducting separate, personal interviews with the social services caseworker, the special educator, the local AYI coordinator, Gloria's school aide, her specialized foster parents, the regional AYI coordinator, Gloria, Gloria's mother, and social workers for the Tribal Association.





# CHAPTER 5

# A Truly Individualized Response: The Story of a Gay Youth

"I want someone to take my eyes out, I don't want to see what's happening to me!" These were the words of Jim Green, a 14-year-old adolescent housed in a psychiatric hospital for unmanageability, prostitution, and theft a few weeks before he entered the Alaska Youth Initiative program. At the time that Jim came to the attention of AYI, he was characterized as an effeminate, artsy, fashion-conscious, engaging, transvestite youth who sought indiscriminate sex with older men. He had engaged in prostitution and shoplifting, and had run away from every residential placement on the continuum of existing services since he had been removed from his home 15 months earlier. Jim had been removed from his home when he reported his father for sexually abusing him. Jim's mother was not able and not interested in providing him with supervision or protection.

## Background

Jim was born in the Lower 48 States. His mother abandoned the family 6 months after his birth, leaving his father to care for three small children. Jim's father sometimes chose to dress Jim, like his two sisters, in girl's clothing. Shortly thereafter, Jim's father was reported for neglecting them. Interestingly, Jim's sisters, ages 2 and 4, were removed by state child welfare and sent to relatives, but Jim was not. He remained under his father's care until he was nearly 7 when his father placed him with relatives. By this time, Jim was already characterized as a "street child" by his relatives. He stayed out late at night, was promiscuous, engaged in shoplifting, and was often truant from school. Jim was the butt of teasing from his classmates for his effeminate behavior, and his relatives requested a change in his elementary school. However, the teasing was not abated by the change, so he returned to the original school for the remainder of the time he spent in his relative's home. Jim was classified as emotionally disturbed (ED) by these elementary schools.

Jim spent several years living with his relatives. He later related that leaving him there was "... the best thing dad ever did! It was the only time in my life that I had a



childhood!" It clearly was the only time other people took care of him while he was growing up, fed him, and watched out for him; it was the only time he did not have the responsibility for caring for himself.

When Jim was 11, his parents reunited and sent for him. He joined them and four younger stepsiblings. His mother and the stepsiblings were strangers to him. This was the first time he could remember ever meeting his mother. Shortly after he joined them, his parents separated again, leaving Jim to live with his mother, who he felt never liked him. For the next year and a half, according to Jim's account, he was responsible for taking care of the younger children as his mother was frequently incapacitated by alcohol and drug abuse.

In the spring of his 13th year, Jim reported his father, who had recently returned home, to school authorities for physically and sexually abusing him. Jim was removed from his home and placed with a paternal relative. His father fled the state to avoid prosecution. Again, Jim was subjected to frequent teasing and verbal abuse from his relatives for his sexual preference and his cross sex-role identification, and he received a beating from his uncles for causing his father to leave the state. He then ran away to live on the streets and seek male companionship. Two months later, he was adjudicated as a ward of the state for protective supervision and was placed in a foster home.

By age 13, when Jim was removed from his home, he already had an extremely long history of neglect and abuse and was a very experienced street child involved in homosexual activity. During the next year, under the care of the state, Child Protective Services was not able to find a single, viable residential placement which could provide psychological and educational services for him, although they attempted every available alternative. Between the time he was first removed from his home and became a ward of the state until his adjudication as a delinquent one year later, Jim had a total of 11 failed placements; he had five failed foster home placements, a short residence at a youth shelter, two separate trials at an intensive treatment center, and three 30-to-45-day hospitalizations in secure units at two psychiatric hospitals. He ran from every foster home, from the treatment center five times, and from one of the psychiatric hospitals. He spent 2 months on the streets before he was apprehended, placed in a secure detention center (his fourth institutionalization within that year), and adjudicated delinquent at age 141/2. He was adjudicated delinquent for behavior during a minor incident (biting a staff person's hand and breaking a mirror) which had occurred during an attempted escape 6 months earlier. His family service evaluation for the court concluded:

[Jim is] a child who has been abandoned by his parents the major portion of his life and sexually molested by his father . . . As a result of these traumatic events, Jim has experienced serious emotional problems. He is unable to trust . . . is



depressed . . . [and] has issues of unresolved anger and abandonment directed at his parents and at society in general.

After his adjudication as a delinquent, Jim was housed in a locked psychiatric facility for 6 weeks until he could be accepted by AYI. During the previous year, he had run away from residential placements on 15 occasions, had lived on the streets for extensive periods of time, had engaged in shoplifting, truancy, and cross-dressing, and was caught soliciting and having sex in a public restroom. He loved the thrill and excitement of living on the streets. He had experienced derision, name calling, and abuse his entire life for his sexual orientation and behavior, including, by his report, his family members who called him "an ugly, stupid faggot, of no value to anyone." Later, he could remember only one foster parent who had told him that it was okay to be gay.

Jim had spent relatively little time in school throughout his childhood and adolescence. When he was in school, he was labeled ED (emotionally disturbed) or LD (learning disabled), and received his education primarily in segregated classrooms. He was functioning between the second and fourth grade levels for basic academics at the time he was admitted to the Alaska Youth Initiative Program, the summer of his 14th year.

# Alaska Youth Initiative: Services and Outcomes

From the psychiatric hospital, Jim was placed by AYI in a specialized foster home with a couple who were experienced parents, both as natural parents and as foster parents. One of the parents also was an experienced health care professional. These foster parents lived in a suburban area in a very well-kept, attractive, middle-class home. They had a 13-year-old foster daughter when they took Jim.

Jim's Core Services Team was formed from representatives from the departments of mental health, probation, and education. His team included his foster parents, AYI coordinator, a case manager, probation officer, special education teacher, and Jim, who was an active member of the team. The overall goal of Jim's treatment plan was to establish stability in his life. Specific goals were to: (a) establish residential stability; (b) establish stable interpersonal relationships; (c) establish responsible behavior regarding sexual practices by addressing issues of exploitation, relationships, and personal health; (d) establish educational stability so that Jim could master basic academics; (e) establish work experience and vocational skills so that he could be self-supporting as an adult; and (f) promote personal development, improved self-esteem and personal trust. Jim was to attend a special segregated school.

During the first 4 months, Jim ran away from his foster residence 10 times, spent 2 days on two occasions at the juvenile detention center, and, after apprehension in the women's restroom at the airport dressed as a woman, was brought to court and placed



for 30 days in a closed psychiatric hospital until case disposition for probation violation. Following every runaway, Jim's foster parents would actively look for him and retrieve him. They were the only ones who ever had done that. They felt this was an extremely important way to communicate to him that they cared about him and that they were serious about providing him with a home.

Following his apprehension in the women's restroom, the court considered institutionalizing Jim for being a chronic runaway, but agreed to return him to the special foster placement at the request of AYI and of the foster parents. While he was in the institution, the foster parents had initiated discussions with Jim in which he told them that they were being too strict with him. From his perspective, they gave him altogether too much supervision, going with him everywhere he went, and demanding to meet every friend.

Based upon their discussions and some negotiation, the foster parents decided to change Jim's behavior program to give him more responsibility and autonomy. Whereas they had previously taken his shoes away to prevent him from running away in a cold Alaska winter, they bought him very expensive new boots unlike any he had ever had before, coming from a very low-income home, and told him that he was responsible for caring for them. He told us later that his foster parents taught him to hang on to his things and to take care of them, whereas in the past everything had been transient and disposable. They also bought him a bus pass to get around the community independently, relaxed their behavior management program, and gave him greater freedom.

Jim's foster parents also decided to actively support Jim's sexual preference and to promote his personal interests and choices. They found and obtained a gay therapist who could provide Jim with information and be a role model, and they began an adolescent gay support group by placing advertisements in newspapers and flyers, and by contacting school counselors. Jim's foster mother acted as the co-facilitator of the support group with the gay therapist. The foster parents attended Gay Balls with Jim and encouraged him to bring his friends home to meet them. They assisted him in finding opportunities to further his interests in cosmetology by helping him attend career classes, go to modeling school, and try out for a fashion show.

The Core Services Team and Jim's foster parents provided opportunities for him to become educated about health and safety issues, about how to develop meaningful relationships, about how to avoid exploitation, and about how to safely pursue his sexual preference. They obtained services from a therapist of Jim's own choosing, a man whom Jim had met and liked during one of his hospitalizations. He and Jim met twice a week around biological family issues and gender issues. The team and Jim's foster parents encouraged AIDs testing every 6 months. They also explored



extracurricular activities of his liking and, at his request, they bought him a membership to an athletic club which he attended three times a week.

In effect, the foster parents adopted, internalized, and exemplified the AYI philosophy of unconditional care. His foster mother said:

We gave him unconditional acceptance. No matter what would happen, we would find him. He was so unloved, so rejected. He lamented the loss of his family . . . [He] made so many attempts to build a relationship with his mother, his grandparents, his sisters, yet he was so rejected. We actively looked for him. We were the only ones who ever did! . . . Parents who care can make a great difference!

During Jim's interview, he evaluated living with these foster parents as very valuable. His foster mother showed that she really cared about him, taught him trust and self-respect. She stood up for him publicly against a teacher who had pushed him around in school, and she got the teacher suspended. Jim was extremely impressed by this. No one had ever stood up for him before. The Core Services Team supported the foster parents' initiatives for backing Jim. The team approved and paid for the services that were needed and provided personal support and appreciation for the foster parents' work.

From the day Jim returned to the foster home after his release by the court until the day he left for good 18 months later, he had no further runaways. Throughout that time, he continued to be actively interested in homosexuality. He continued to fantasize about having a wonderful relationship with an older man, and he experienced further incidents of personal exploitation by older men. Eight months after he began to live with his foster parents, he had a one-time contact with a doctor who professed to love him and by whom he was quite smitten. The doctor then harshly rebuffed Jim when he attempted to make further contact. Subsequently, Jim left his name in restrooms and received calls at home. He subscribed to a gay magazine and corresponded in writing and by phone with a man he met through this magazine. Then a high court official who had met Jim and a few other boys through official business, befriended them and had them to dinner frequently until it became known that the man was sexually engaging them.

With informal counseling at the foster home and formal counseling and services related to issues of exploitation and mutuality in relationships, Jim gradually became more interested in peers. He began to bring friends home to meet the family and he developed friendships that lasted for many months. His first peer friend came down with AIDs. After they broke up, he became friends with a college student who would visit the family and with whom he spent a lot of weekend time.



During Jim's first year in AYI, incidents of cross-dressing decreased dramatically and occurred generally only after stressful situations. After one unauthorized overnight, he appeared for his team meeting in drag with a blond wig as "Delia." During the second year, he cross-dressed only twice. After the break-up of his first peer relationship, he took his \$100 clothing allowance and bought a complete outfit of women's clothes. He returned them to the store the next day, however, exchanging them for appropriate clothing. The second instance of cross-dressing occurred following an acute illness of one of the foster parents.

After one year in special foster care, Jim asked to take additional classes at school: figure skating, piano, and weight lifting. He also attended a safe sex seminar and took a 3-month modeling course. By the New Year, Jim was requesting jobs and responsibilities at home to earn money, he began attending a regular high school, he came home promptly after school on a regular basis, and he finished his modeling course. He later said that the modeling course was one of the best things he ever did; it taught him how to walk, talk, and dress. During the interview conducted for this study, he was very appropriately dressed and presented himself as a bright, mature individual.

By the end of the second school year with AYI, Jim was receiving consistently excellent evaluations. At home, he was beginning to do more problem solving and exploded less frequently. His foster parent stated:

Jim continues to do well...only two restrictions in the past 3 months; one for coming home one-half hour late, and one other time an hour late. He lives by the rules of the house in a generally pleasant manner. I feel that in the past 2 years he has made tremendous strides in being able to deal with authority figures, at home at least. He is very willing to say he is sorry... and it is extremely rare that he has a temper outburst. He has not run in an entire year. Jim continues to have trouble with lying and stealing, although stealing is confined to the house. The wild, elaborate stories he used to tell us have stopped. We feel good about Jim's progress. He really is a very pleasant person to have around.

By the second summer, Jim got and kept a cleaning job in a motel. He continued to work there part time when he reentered school. After one month of both working and attending school, he refused to return to school, requesting to work full time and to keep all the money he earned. He was told that if he worked full time and did not attend school, he would need to pay for his room and board at the foster home. He was encouraged to return to school and get vocational counseling, but refused. He worked until mid-October and then left abruptly by plane for the Lower 48 States.

During his interview, Jim told us that he had always been fascinated by San Francisco. When he watched the big San Francisco earthquake and its aftermath on TV, he felt that this was the time to go. So he took his money and began a 9-month odyssey



around the country which included visits to Chicago, Florida, Texas, San Francisco, Los Angeles, and Pennsylvania. He also made brief visits to the relatives with whom he had lived as a child and to his father. Throughout this entire time, he maintained contact with his foster parents by phone, calling almost daily as he traveled, eluding police and social service workers, and refusing to return to Alaska. He reported that he was able to find work and was able to access social services and support as he needed them. State custody was terminated when Jim refused to return. He was 17.

Six months later, Jim voluntarily returned to his foster parents' home where he stayed for a few days while he found housing at a shelter and got a job at a hotel. Later, he got housing with a friend. He continued to have frequent contact with his former foster parents. At the time of this study, he was having lunch downtown with his foster mother on a regular basis several times a week. He related proudly that his "mom" was very proud of him for how well he was able to manage for himself and to travel throughout the United States safely for 9 months.

### Evaluation: What Made It Work?

Core Services Team members felt that the goals of Jim's AYI treatment plan were to a large extent fulfilled over the 2 years he was in the specialized foster home. During that period, stability was achieved – stability in residence and stability in education. Jim felt a part of the foster parent home, and developed trust and respect as well as a sense of belonging rather than continuing to have the sense of abandonment which he had so often experienced. Jim felt supported by the Core Services Team. The goals of providing safety and education around issues of homosexual practices and of developing appropriate relationships versus exploitation also were achieved. The age of Jim's sexual partners decreased, cross-dressing was eliminated, Jim did not contract AIDs, and he engaged in regular, voluntary AIDs testing. By Jim's report, he learned to respect himself, to be more selective in his relationships, and to make demands and place limitations on others within these relationships. He also reported that he experienced less personal exploitation.

Furthermore, Jim was able to pursue and develop his own interests (e.g., the modeling school and the health club) which contributed to increased self-esteem. His education about dress and decor supported him in being the person he wanted to be. Jim evaluated the modeling school as "tops." "Modeling school taught me maturity, how to dress, how to act, how to be, how to talk, how to walk." Jim was also able to obtain and keep paid employment. However, his vocational preparation was not adequate to provide him with a useful skill nor was his educational experience sufficient to lead to mastery of basic academic skills. He was subsequently only able to hold entry level, custodial jobs.



When Jim came for the interview, he was a tall, slender, nice looking 17½-year-old youth, with short, wavy hair. He was casually, but neatly dressed, and looked as if he were the son of any respectable, middle-class family from Main Street, USA. Jim was congenial, friendly, and very open during his interview. He was verbally fluent, well-mannered, and appeared self-confident and intelligent. He also was talking about working on his GED.

As a result of his experiences during his time with AYI, Jim showed a big improvement in maturity. He learned to accept responsibility for himself, he asked for help in obtaining Supplemental Security Income (SSI) and Medicaid, and he obtained his own job and his own residence while remaining in contact with his primary AYI support, his former foster parents.

Jim Green was a recipient of AYI services for 2 years and 5½ months, from age 14.5 until 17, when he was discharged. He had only one residential placement during this period, with his specialized foster parents with whom he lived for 2 years and 2½ months. All parties interviewed, including Jim, felt that the AYI experience had been extremely beneficial and successful.

The factors identified as leading to this success were as follows:

High quality direct care providers. Jim's foster parents were supportive and flexible. They both taught and modeled mutual respect and regard. According to Jim:

Mom showed she really cared for me. I learned a lot from the Greens, how to trust! Most of my life things have been thrown away. They taught me to take care of things and hold onto things. Mrs. Green stood up for me against one of my teachers. She believed in me... I've stayed with the Greens 2 years, the longest I have stayed anywhere. They taught me to care, to be attached. When I left, I was really sad, but I learned an awful lot by being on the road. My mom (foster parent) was impressed at how I worked it out, planned it, and was able to take care of myself.

Unconditional care. Jim's foster parent said, "No matter what happened, we would find him. He was so unloved by his family and he tried so hard to build a relationship with them. He was so rejected." These foster parents not only went after Jim and brought him back time after time, they also learned to listen to Jim, to respect and support his sexual preference, and to communicate their respect and support for him as a person.

Facilitating Jim's interests. Jim described the teachers in the segregated school as being very helpful by helping him with his interests in fashion and by providing him with support and attention. His foster parents supported him in his interests and ideas in many ways, modifying the behavior program, attending gay dances, beginning the gay adolescent support group, paying for modeling school. His foster parent said, "We



changed the way we dealt with him, gave him more responsibility, and helped him obtain his objectives rather than ours."

Youth participation in planning. Jim reported participating in planning meetings with his Core Services Team. He said that they did listen to him, that he was part of the decision process, and that what he got was good.

Receiving counseling and support around sexual preference. In addition to highlighting the positive influence of his foster parents, Jim identified his therapist as being instrumental in teaching him how to express himself, how to open up, and how to communicate. In all, he received 3 years of counseling on identity and sexual issues.

Core team planning, coordination, and support. Jim's foster parents said, "Working with the AYI core team was extremely helpful. Team members had respect for our opinions and supported us. We had an extremely positive relationship, unlike other foster parents who always have very negative things to say about their social workers." There also was good communication and cooperation via core team meetings.

## Barriers To More Effective Services

Several issues were identified that created barriers to Jim's social adjustment. Respondents in this study identified the following as being the most significant barriers:

Prejudice towards gay people. Society puts many barriers in the way of homosexual youth and teenagers. These were seen as significant impediments to Jim's adjustment. He met prejudice and rejection everywhere. Although he attempted to maintain contact and acceptance from extended family members, throughout his career in the social service network and even after he became independent, he was repeatedly rebuffed and rejected. He met prejudice from his major teacher in high school due to his sexual preference. He noted that only one foster parent before AYI had accepted his being gay, saying that it was okay. Societal prejudice and its desire to suppress or repress homosexuality was reflected in a lack of activities for gay youth, by the reluctance of others Jim's age to acknowledge their homosexual interest, and by open discrimination manifested by some school staff, by family, by peers, and by previous foster parents. He also experienced a great deal of exploitation from older men beginning in early childhood.

Lack of effective vocational training. There also were difficulties related to finding work opportunities for an individual with a low level of academic skills. Schools need to put greater creativity and effort into providing useful vocational



training. Jim appeared quite mature and intelligent, but his significant lack of basic skills will surely continue to be a severe problem for him.

Lack of individualization in education. At times, there also were barriers in the school system. Individualization in Jim's educational setting often was missing, and school personnel were sometimes willing to give up on this youth.

#### Conclusions

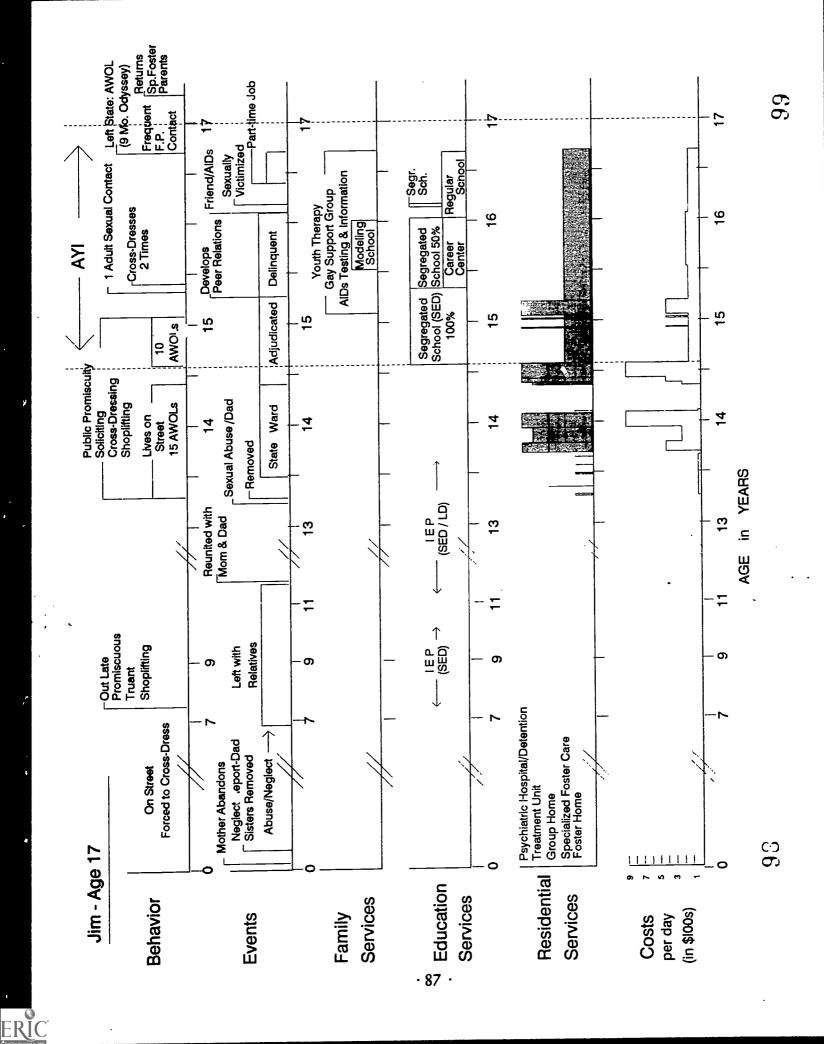
The summary of Jim's case history is shown on the multiaxial timeline that follows and reports his behavior, the major events in his life, and his residential, educational, and service histories. As this chart clearly shows, although Jim received some special education services in elementary school (primarily segregated classes with other children having and showing difficulties), Jim received no family services until adolescence, despite a history of abuse, neglect, and unmanageable and truant behavior throughout his childhood. At that point in time, all services traditionally available were ineffective in bringing Jim under control and "in from the cold," and Jim was at the point of a long and expensive hospitalization or institutionalization. The initiation of coordinated, individualized planning and services built around this youth as well as the recruitment and support of very competent and determined specialized foster parents who internalized and lived the philosophy of "unconditional care," helped Jim develop some stability, trust, and both mutual and self-respect. The 21/2 year period during which Jim was in the AYI program was the longest period of stability he had yet experienced.

Although Jim acquired skills in personal care and personal presentation and he largely eliminated inappropriate and illegal behaviors, he nevertheless faced adulthood deficient in both basic academic and job skills and had a very small social support network, primarily made up of his former foster parents.

On the following page is a multiaxial timeline which shows visually Jim's history: behavior, life events, and services.

Sources of Information: This case study is based upon information obtained from an extensive review of Jim's records and from personal interviews with the youth, his specialized foster parents, the local AYI case manager, the AYI Regional Coordinator, and a school administrator.





# CHAPTER 6

# A Cry for Help: Two Cases of Youth Labeled Borderline Personality

This chapter tells the story of two very different but very disturbed young women who carried the psychiatric label of borderline personality. One young woman had a lengthy history of sexual abuse and multiple placements beginning in very early childhood. The other grew up in her family and community with no apparent problem or unusual circumstances until one day when she suddenly and permanently left her home and family and began a period of revolving through an endless succession of services. By their mid-teens, both young women had exhausted the social service resources available in Alaska, and had ended up in out-of-state, long-term, restrictive residential institutions. These are their stories.

# Case: Mary - A Successful Community-Based Alternative to Psychiatric Hospitalization

A letter written to an investigator in the Office of the Ombudsman by Mary's courtappointed guardian ad litem to remove Mary from AYI and return her to an out-ofstate residential program stated:

I am writing this letter to request an investigation of the management of the case of [Mary] by the Alaska Youth Initiative Program . . . Four of the children I represent as guardian ad litem have been involved with [AYI]. In each case, the AYI process has been dreadful to navigate, the practices have been inconsistent, and, most unfortunate of all, the program has been unsuccessful in its stated goal of providing appropriate, holistic care for these severely damaged children within the state of Alaska, thereby preventing out-of-state care. These children are being maintained within the state; the care for them, however, has been woefully inadequate.

This case epitomizes the discrepancies between the ecologically based, wraparound philosophy of care employed by AYI and the medically based, psychiatric care that is administered to many children with severe emotional and behavioral problems.



A psychiatric evaluation that was conducted just prior to Mary's return to Alaska diagnosed her as having a conduct disorder, undifferentiated type, and a borderline personality. In addition, she was approximately 7 months pregnant. For the protection of the baby, and in order to provide optimal treatment for Mary, the evaluation ended by recommending that the state of Alaska obtain custody of the baby and that Mary receive long-term care in an inpatient psychiatric hospital. AYI chose to pursue a very different course of treatment.

For a child or youth to be in out-of-state residential care with a diagnosis of conduct disorder and borderline personality, there is almost always a history of severely aggressive, self-destructive behavior. In Mary's case, this included heroin use, many AWOLs from several institutions, sexual promiscuity, suicide gestures, homicidal ideation, and a threat to kill a staff person with a knife. In most of these cases, there also is a childhood history of severe, if not brutal, physical and/or sexual abuse combined with an experience in the service delivery system that can only be characterized as further abuse and neglect. Once again, Mary's case is no exception.

# Background

While there are only limited details regarding Mary's early childhood, it is clear that it contained much trauma and instability. When she was born, her parents lived in a small, isolated community with few resources. Her parents were divorced when she was approximately 1 year old, and custody was awarded to her mother. Her mother had a severe alcohol problem which periodically caused her to place Mary with others. For the next several years, as her mother's drinking became out of control, Mary lived for short periods of time with her maternal grandparents, her mother's boyfriend, and a receiving home for abused and neglected children.

When Mary was 4½, her mother asked that the child welfare agency place Mary in a foster home. The severity of Mary's mother's problems and her instability were exemplified 2 months later when, while intoxicated, she forced herself into the foster home and took Mary to a local bar. It took two police officers and a social worker considerable time to convince her to return her daughter to the foster home. Shortly thereafter, Mary's mother faded out of the picture, leaving only periodic reports of chronic drinking, alcohol overdoses, suicide attempts, and hospitalizations.

Over the next several years, Mary experienced multiple placements with different foster parents, her father, and her grandparents. This instability was largely a function of a custody dispute between the two sets of grandparents which was further complicated by reports that all her grandparents experienced rather severe alcohol problems. At the



age of 7½, Mary was returned to the custody of her father. This was shortly after he had remarried and become the father of a second daughter.

At the age of 9, Mary reported to her stepmother that her father had been having violent sexual intercourse with her on a regular basis over the previous 18 months. The allegations included being beaten and tied up as well as being sexually assaulted. The stepmother confronted her husband who denied the allegations. She then told the paternal grandparents who called Mary a liar and made her apologize. Approximately 2 months later, the stepmother notified the child we'fare agency, whereupon the allegations were substantiated.

The child welfare agency obtained emergency custody and placed Mary with her original foster parents. Mary's father eventually pled guilty to charges of sexual abuse in the first degree and was incarcerated. Several years later, Mary disclosed to a counselor that the abuse began when she was 3 years old and included forced oral sex.

From the time of her emergency foster home placement at age 9 until she was accepted into AYI at age 15, Mary experienced a minimum of 10 placement changes. This included six foster-home placements, a placement with her stepmother, two group-home placements, a placement in a detention center, one in a psychiatric hospital, and two in out-of-state, residential treatment centers. In general, the restrictiveness of the placements increased with the severity of Mary's behavior problems. Each placement change resulted from people's inability to cope with various forms of Mary's acting-out behavior.

In the early stages of this 5-year struggle to obtain a suitable placement for Mary, she was transferred from one foster home to another for behaviors such as noncompliance with rules, theft, and inappropriate interactions with men. These interactions fluctuated from Mary's fears of being raped to acting sexually provocative with strangers. One example of an incident that prompted a placement change was Mary's allegation that her foster father had tried to molest her. The foster parents notified the child welfare agency that they would not tolerate such behavior and demanded that she be removed from their home within two days.

Over the next several years, Mary "behaved" her way into more restrictive placements through a variety of increasingly severe incidents involving aggression, running away, sexual promiscuity, drug abuse (marijuana, LSD, cocaine, PCP, and heroin), suicide attempts, and expressions of homicidal intent. All this culminated at age 15 when Mary was sent to a second out-of-state residential treatment center. Upon admission, descriptions of her included:

... borderline personality disorder because of a long history of unstable relationships, self-damaging impulsiveness, affective instability, self-mutilating



behavior, and a lack of meaningful sense of self . . . conduct disorder, solitary aggressive type, with mixed substance abuse.

Mary was placed on a locked unit where she received frequent psychiatric counseling and anti-depressant medication (Nortriptyline). A major focus of her treatment was to help her develop trust in her adult caretakers. After 6 months, it was determined that she had made sufficient progress to be transferred to an unlocked, psychiatric wing. One week later, in response to being punished for smoking, she ran away to a large nearby city where she lived with a boyfriend she had met during a previous 3-month runaway from her first out-of-state placement. After 3½ months in the city, her boyfriend, in a fit of anger, reported her to the authorities.

Upon her return to the institution, it was determined that Mary was approximately 2 months pregnant. The pregnancy necessitated an abrupt change in the treatment plan. Officials at the treatment center wanted her returned to Alaska before the child was born. At that point, the child welfare agency in Alaska referred Mary's case to AYI.

# Alaska Youth Initiative: Services and Outcomes

In the process of developing an individualized service plan for Mary, AYI arranged for an independent, psychiatric evaluation prior to her return to Alaska. The following excerpts are taken from this 9-page report:

It is the impression of the staff at [the out-of-state psychiatric institution] that the patient is not fit to be a parent at the present time. Her lack of knowledge of parenting, her dislike for children, her apparent indifference to and strong ambivalence about the fetus, and her extreme mood lability and narcissistic vulnerability have all been cited as evidence for her inability to assume the role of mother. Dr. XX, her attending clinician, believes that if her baby were to cry for any reason the patient would be at risk to become angry and harm the baby.

These concerns have been based in part on the staff's observation of disruptive behavior in other areas of her treatment. She has frequently split various staff, having a tendency to idealize some while devaluing others. She frequently maintains irrational, strong, negative dislikes for individuals who do not agree to her wishes or [who] attempt to point out her deficits. In particular, it is felt that she has a lot of trouble accepting criticism or instruction from authority figures because of her previous negative experiences with abusive caretakers. This problem has persisted since her readmission to [the psychiatric institution] and has frequently been the cause of disruptive, oppositional behavior.

For much of the interview, it was hard to ascertain important facts about the patient's history because of an apparent reluctance on her part to provide them.



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She often became irritable when I attempted to get information about these topics from her. To her credit, she was able to state near the end of the interview when I asked her about this behavior that she has a difficult time trusting people that she does not know. After revealing this information, she became more open and less defensive at answering questions.

At the end of the report, recommendations included the following:

It is clear that [Mary] will continue to need inpatient psychiatric treatment for an extended period of time. She will need a minimum of 6 months and possibly up to 1 year of continued inpatient treatment in a locked facility in order to prevent her from impulsively eloping as she has in the past.

It is highly likely that the prospect of becoming a mother will reawaken unresolved conflicts [and] the patient's psychiatric symptoms will be exacerbated as the pregnancy progresses.

It would be highly dangerous to both her and her baby to have this treatment take place outside of a locked, inpatient psychiatric unit.

The optimal solution would be for the patient to voluntarily relinquish the baby. Hopefully, in intensive therapy she could come to recognize that it would not be in her best interest or that of the fetus for her to assume caretaking responsibility for it. One of the goals in such a therapy would be to help her recognize that she could interrupt the terrible cycle in her family of abuse and neglect that resulted in her own unhappiness and severe dysfunction.

The following quotes concerning Mary's interests appeared in the same psychiatric evaluation, but were not incorporated into the final recommendations:

The patient did not exhibit much emotion when talking about her pregnancy. She stated that she wanted to keep the baby, although it was not clear from her account what her reasons were. She did show some insight when she said that she did not think it would be a good idea for her grandmother to care for the baby. She cited as a reason for this opinion the fact that the grandmother had not done a good job in the past of raising other children.

The patient stated that she would like to get some supervision in raising the baby after it was born. She added, however, that she would like considerable autonomy in managing its needs. She did not like the idea of being in a 24-hour setting where her behavior would be constantly monitored and restricted. She indicated that she would like to live in a group home that would help her develop parenting skills.

It is at a point like this that the ecologically based treatment approach of AYI differs most radically from the more traditional, clinically based approach modeled after the medical profession. In the latter, the assumption is that the child has a "disorder"



which can be treated most effectively by placing the child in a special environment where the child is protected and can have greater access to therapy.

The approach that was taken by AYI was somewhat the opposite. It assumed that the community plays a significant role, both with respect to the problem and to the solution. The objective is to achieve a greater balance between the restrictiveness of the environment and the safety of the youth. Instead of placing someone like Mary on a locked ward with many other "severely disturbed" young people, AYI focused on creating a community placement whereby staff could be "wrapped around" the youth to achieve safety. The AYI approach begins with the needs, attitudes, motivations, and strengths of the young person from a broad, ecological perspective, and then adds safety, rather than starting with safety and then adding the treatment.

With cases as severe and complex as Mary's, it is often necessary to consider the ecology of the service delivery system as well as the ecology of the youth and family. In planning the return of Mary to Alaska, there were forces moving in multiple directions, and the actual scenario that took place was much like a James Bond movie, although no shots were fired. AYI was pushing for a brief stay in a psychiatric hospital in order to provide stability and observation in a controlled setting and to be able to incorporate Mary into the decision making process. If all went well, this was to be followed by a placement into a specialized foster home with intensive, individualized services.

The guardian ad litem, the director of clinical services in one of the in-state psychiatric hospitals, and other professionals were advocating that Mary be placed in a psychiatric hospital until shortly after the birth of the baby, followed by the baby's placement in foster care and by Mary's return to long-term, out-of-state psychiatric care. Placement in a specialized foster home was acceptable to Mary, however, she wanted the placement to be close to the village of her maternal grandparents, and she felt it wouldn't be long before she could manage on her own.

What transpired between the out-of-state placement and Mary's eventual placement in a specialized foster home was anything but routine. The director of the preferred instate psychiatric hospital refused to admit Mary because there was no guarantee that she would be sent out of state for long-term, in-patient psychiatric care following the birth of her baby. Mary was then accepted into a second psychiatric hospital with the understanding (at least by some of the players) that after 30 days she would be transferred to a third, in-state psychiatric hospital.

After approximately 10 days in the second hospital, the director of the hospital's children's unit stated that (a) Mary was functioning at age level; (b) the only diagnosis he could give her was chronic substance abuse, currently in remission; (c) her pregnancy



was developing nicely and she was no longer considered a higher risk than any other teen mother; and (d) that she had a very positive influence on the other patients.

Since the third psychiatric hospital made it clear that it would not admit Mary without an updated diagnosis, AYI had Mary flown to a group home in another part of the state. To AYI, it was to be a brief stay prior to establishing a placement in a specialized foster home. To others, it was a unitateral decision that was not in the best interest of the young woman. A petition to the court and many last-minute phone calls were made to AYI, the child welfare agency, the family, and the airport to try to stop the placement. However, none of those efforts were successful.

Shortly after the birth of her child, Mary was placed in a foster family with a 2-year-old child. The foster parents were skilled professionals who had been administering a group home of persons with developmental disabilities. Other characteristics that led to the selection of this particular family were the foster parents' minority status, their unconditional commitment to help Mary, and the opportunity the foster parents had to model appropriate parenting skills on an everyday basis. AYI was able to obtain these parents by helping one of them find a job in a community mental health center.

The Core Services Team consisted of the foster parents, the child welfare caseworker, a mental health counselor, and the guardian ad litem. Mary's input was provided primarily through the foster mother. The following are excerpts taken from the report of a Core Services Team meeting that took place shortly after Mary's foster care placement. These excerpts illustrate the AYI approach to individualized needs assessment across service domains.

Safety - Mary has consistently shown she is not a danger to herself or others.

Behavioral/Psychiatric - Mary is not taking any psychotropic medications or exhibiting symptoms which would suggest the need for medication. She would benefit from supportive counseling. Outpatient psychotherapy should be part of a comprehensive treatment plan that should include attending sessions of Parent Aid and Narcotics Anonymous.

Residential - The [foster parents] report that Mary is doing wonderfully well in their home and is adequately taking care of her child. Her placement with the [foster parents] remains stable.

Educational/Daily Structure - Mary needs to spend time with [her baby]. Most of her daily structure revolves around child rearing responsibilities. In addition, Mary needs to pursue a GED and explore the possibility of attending beauty school.

Social/Recreational - Mary is in need of socialization with single mothers of approximately the same age. Furthermore, she is in need of having access to age-appropriate social events.



Medical - Any needed follow-up medical care will be provided through the [foster parents].

Legal/Judicial - There are no unmet needs in this area.

The review of this case took place approximately 5 months after Mary had been placed in her specialized foster home. At that time, her adjustment continued to be remarkable. She was relating to her baby in a very appropriate manner, she was receiving counseling at the community mental health center, she completed her GED and gave the commencement address at the graduation ceremonies, and she was developing a small network of friends in the community.

During the interview with Mary, she appeared comfortable and relaxed. She seemed to enjoy the opportunity to discuss the services she had received, and she softly, but assuredly, made the following observations. Interviewers' questions are indicated in bold.

Most of the people who tried to help me were nice. I just wanted to do my own thing. It got to the point where no one could handle me. I always thought that if I had something good I could get something better. My biggest problem was taking off and drinking.

In some places, I felt they should have separated the kids. Some kids were very messed up, and others were just behavior problems, like me.

Some of the programs weren't strict enough and if you wanted to leave all you had to do was walk out the door.

## How should someone work with someone like you?

Enforce the rules more and don't give up!!!

Going out of state scared me. I didn't want to leave Alaska. In the first program, I hated all the rules and there were no boys. There were about six cottages with 20 girls in each. Someone could have gotten a lot out of it, but not me. I don't get along with a lot of people, especially girls. Girls are mostly stuck up. The second program was good. I hated the rules but they helped me. One time I had to face a wall for 72 hours straight. I did it, but I hated it. When I did good, I got rewards. I got to the highest level. I could come and go, do anything. Then I got in trouble for smoking, lost it all, and ran away again.

#### What was it like to live on the streets?

I thought it was fun at the time. New I think it would be horrible. Other kids were doing it and I wanted to be part of it. The scariest was the drugs (you don't know what's in them), and being by myself when my boyfriend was somewhere else. I was paranoid at the time, but now I don't think anyone



knew I was a street kid. Parts of it were fun; different people and a lot more things to get into. My boyfriend had a job. When he was off his job he sold drugs. It was not a good relationship and he finally turned me in. He said that if he wasn't going to stay with me, no one was. Some of the people I met were weird and would take advantage of others. I learned to get tough. At times I would call my grandmother to let her know I was okay.

There was one person in that last place that I really liked. Our relationship went past all that professional stuff. She said that when I left, she would quit. I've tried to call her by the 800 number, but she's gone.

I didn't want to run while I was pregnant. I wanted to stay out of state, but they said I couldn't keep my baby. I wanted to live on my own with some supervision. They said they bet I would give it up in 6 months. That made me mad. I learned my grandmother wasn't drinking anymore and I wanted to go be with her. I still do.

I like my foster parents and I like it that the only restriction is no alcohol or drugs. That's no problem. Even the thought of alcohol makes me sick. But I can't wait to get on my own. Everything here belongs to everyone. It's kind of hard. I would like my own apartment. Even though it will be hard to be on my own, I will like it better. I may go to college in September if I can get financial assistance. I think I'd like to go into psychology. I don't want to be a secretary! School is not hard for me. The hardest thing is the teachers.

Although Mary was attentive and motivated throughout the interview, it was clear that her primary concern was her baby who was sleeping in the back room. Periodically during the 90-minute interview she would stop talking because she thought she heard him waking up, and on two occasions she excused herself and went to the bedroom to make sure he was all right.

## Evaluation: What Made It Work?

Unconditional commitment to the AYI philosophy. What stands out in this case is an incredible commitment to the overall philosophy of AYI. In spite of strong resistance, the Core Services Team maintained the ability to listen to Mary and meet her needs in the least restrictive environment possible. The importance of unconditional care, teamwork, flexible services, community-based care, and positively focused care were all a critical part of the success of this case.



# Barriers To More Effective Services

Over-reliance on the medical model. Much of the resistance to Mary's service plan came from professionals who were committed to the medical model. Several aspects of this case are instructional with respect to such a model. First, it was clear that, at least in the short term, the predictions made in the psychiatric evaluation were wrong. It was clearly stated that Mary would need an additional 6-12 months of inpatient psychiatric hospitalization before she could make a reasonable adjustment to less restrictive services, and that, in her present condition, she would be likely to neglect or harm her baby. This position was understandable given the assumptions of the medical model: If the treatment isn't working, the treatment needs to be intensified.

The second instructional aspect of the case was AYI's commitment to meet Mary's needs in the least restrictive environment. At no time did AYI conclude that Mary would no longer display severe behavior problems or that there was no risk for her to harm or neglect her baby. Rather, AYI concluded that it could more effectively meet her needs by working closely with her in the community. She was gradually phased into the community, she was allowed to participate in developing her service plan, and she was made aware that additional supervision and other services were available, if needed. The AYI commitment to unconditional care and the utilization of flexible funds and flexible services were exceptional in this case.

Finally, this case illustrates how much more needs to be learned in efforts to serve children who are experiencing severe emotional and behavioral problems. How many children continue to reside in highly restrictive, psychiatric and residential services because their "disorders" require more treatment? Even if Mary's adjustment deteriorated overnight, the important question was whether or not some of these more radically different approaches for individuals like Mary should be pursued. Given the absence of empirical support for the effectiveness of more restrictive, medically oriented services, we believe that children like Mary will have more of a chance in programs like AYI.

## Conclusions

In many ways, Mary's case illustrates the inability of the present service delivery system to meet the needs of its most challenging children. Having been badly abused and neglected early in life, Mary developed severe behavioral and emotional problems. At an early age, she was placed with a variety of relatives and foster parents. While these placements were well intentioned, it is doubtful that any of the various caretakers had the special skills or experiences needed for coping with the behavioral and emotional



problems Mary displayed. It was also doubtful that they received any training or professional support to make up for their lack of experience. What was certain was that, as Mary's problems escalated, she was moved from one placement to the next, until she ended up in a psychiatric institution several thousand miles from home.

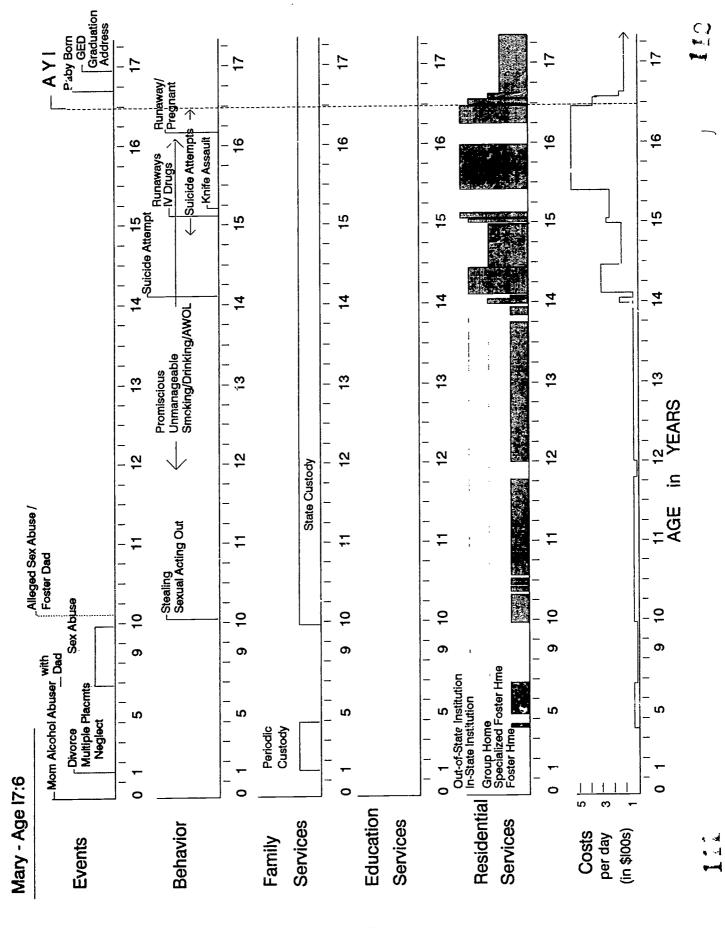
AYI's response to Mary was anything but business as usual. While other cases that are part of this evaluation were as creative and innovative as this one, this case most exemplifies the persistence and commitment of AYI to the principles of individualized services. Given the forces of the "professional establishment" that were moving towards the separation of Mary and her baby, and the predictions of extreme harm that would occur if that didn't happen, it is remarkable that AYI was able to administer the individualized, wraparound services that it did.

While Mary and/or her son may have serious adjustment difficulties in the future, it is hard to argue that the AYI services which had been provided by the time of this study were not superior to the services she would have received through another year of psychiatric hospitalization. This is not to say that the AYI services could not have been improved (although no one suggested how), nor that the services would have been as beneficial for any other child or youth in a similar situation (although that is certainly possible). It is also not to say whether Mary and her family would have been better off had she received individualized, wraparound services at a much earlier point in her childhood. While a service delivery system cannot afford to "wrap" intensive services around all, or even most, children and families who might benefit from such services, it would seem that this could and should be done in those cases where there are pronounced (and empirically documented) at-risk indicators for the occurrence of future dysfunction. Clearly, that was the case for Mary and her family.

The multiaxial timelines on the next page visually represent the major events, behaviors, services, service costs, and outcomes related to Mary's case.

Sources of Information: Information for this case was obtained by reviewing case records and by conducting separate interviews with Mary, the specialized foster mother, the director of the children's unit at a psychiatric hospital, and AYI staff.





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# Case: Gretchen - Who Will Help Me?

We met Gretchen, an articulate 19-year-old woman, in her apartment in a moderate-to-low-income area in a city. She was dressed very neatly in an attractive, color-coordinated outfit which was in marked contrast to the state of her apartment. The latter was a shambles. It looked like a cyclone had raced through each room as well as through the kitchen cupboards. We paid no heed to the disarray, nor did she make any mention of the state of her living quarters. Gretchen's arm was in a brace.

"I'm accident prone. I broke my glasses and rode my bicycle into a lamp post." Gretchen was very "accident" prone, hurting herself intentionally or accidently continuously throughout her adolescence. "She is always in a cast or a brace," according to her mother.

When we talked about the problems she'd faced since early adolescence, Gretchen responded:

At first I didn't want help. I was paranoid and I wouldn't talk. It was hard for me to talk, to get me to talk. After a while [after enumerable admissions to psychiatric hospitals], they never believe anything you say. They finally told me, "Go kill yourself and do it right!"

One out-of-state placement was described as:

... a really lousy place. If you do something wrong, they lock you up in "timeout." I was in there for 24 hours. They had no restraints and they let you abuse yourself. I cracked my head so badly they had to send me to the hospital. Then they sent me back [to Alaska].

When asked about her future plans, Gretchen said:

I have exhausted all possibilities for help here [in this state]. I need to get out, go to Seattle, find someplace where I can get help. Find someone willing to help me. The sheriff is the only man I can trust. I used to call him often. He is in . . . now. No one here listens. No one here is willing to help me. I need to get a job to earn enough money so that I can leave [Alaska].

Gretchen, at 19, has a 5-year history of suicide gestures and attempts, of sexually self-abusive acts, of violent and destructive behavior, and a high rate of "accidents." She had an eating disorder, was angry, depressed, anxious, and paranoid. She continued to say that there was no one to help her, that no one listened to her, no one believed her. She made many allusions to suicide. She was still looking for someone else to save her.

Gretchen's psychiatric diagnoses included: attention deficit disorder, hyperactivity; major depression; and borderline personality.



# Background

Gretchen grew up in a small town in a traditional Middle American, middle-class family with her two parents, two brothers, and a sister. Her mother was the primary care provider and homemaker, while her father was employed outside the home. In kindergarten, Gretchen was identified as hyperactive and was treated with Ritalin. This medication was discontinued by first grade and, according to her mother, neither hyperactivity nor any other issue related to school, home, or peer relations presented any concern for quite some time. When Gretchen was 9, the school notified her parents that they were seeing some behavior changes indicative of adjustment problems. There were no signs of behavior change at home, however, and this appeared to be a time-limited issue. According to her parents, Gretchen continued through elementary school with no further difficulties. She attended school regularly and received good grades.

Suddenly and dramatically, everything changed. In the late spring of her seventh grade, Gretchen became despondent at school and began seeing the school counselor. The principal notified Gretchen's parents that she was suicidal. A few weeks later, Gretchen got up from the dinner table and left home. She has never been home to spend the night since. She lived on the streets and with friends throughout the next 4 months, the summer, and the fall of her 14th year. As soon as she was taken back home by her parents or by social services staff, she would run away again. She ran away from home 30 times in the first 4 months. Her parents were extremely upset, frustrated, and distressed at their inability to find assistance for their daughter and for themselves. She had committed no crimes and was therefore not eligible for any services, nor could they forcibly restrict her movements.

After nearly 5 months out of her home living on the streets, Gretchen attempted to commit suicide in the local mall by taking a drug overdose. She was admitted to a local community youth group home and then released in the custody of two teenage friends. Her frantic parents, with the assistance of Tough Love, took her forcibly to a distant psychiatric hospital 2 weeks after her suicide attempt for a 3-day observation. She remained there in treatment for 2 months. Twice a week, her parents drove several hours each way to attend family therapy at the hospital. Gretchen, however, refused to participate in therapy with her parents. She admitted later that she was very paranoid at that time and would not talk to anyone, particularly her parents, during family therapy. She was released to the local community youth group home after 2 months, but was readmitted to the psychiatric hospital within a few days for extremely self-abusive, self-destructive behavior.

During the next 8 months, Gretchen cycled back and forth six times between the psychiatric hospital and the community group home. Following her eighth failure at



the community group home, she was admitted to the local hospital where she remained under guard until they could send her back to the psychiatric hospital. She had eaten some broken light bulbs. After another 30 days in the psychiatric facility, her eighth such admission, she returned to the local group home and, in a matter of days, failed once again. She then was sent for 3 months to an intensive youth treatment center in another county.

Following repeated runaways, assaults, and suicide attempts, Gretchen was admitted to a second psychiatric hospital. During this entire period, her violent and self-abusive behavior had frequently resulted in the use of 4-point restraints for long periods of time. She repeatedly put broken glass and other objects up her vagina, threatened or attempted suicide (taking large amounts of aspirin substitutes), and became violent and aggressive when restrained.

During the 21-month period between when she left home at age 14 nd when she was accepted into the AYI program just short of her 16th birthday, Gretchen, by her own admission, had refused to cooperate in any therapeutic endeavor. However, she also blamed "them" for "letting me run away." In fact, when Gretchen ran, she did so carefully, so as not to get hurt. According to a social worker who knew her, she hung around police stations and policemen, and managed to get picked up so as not to be out over night.

Gretchen was described at this time as angry, depressed, highly accident prone, manipulative, violent, destructive, sexually self-abusive, threatening suicide, and paranoid. She also had serious eating disorders. She ran away from every nonrestrictive setting. There was no evidence, however, that Gretchen was involved in drugs or promiscuous behavior. Just prior to her 16th birthday, 2 years after she had first run away from home, she was accepted into the Alaska Youth Initiative program.

#### Alaska Youth Initiative: Services and Outcomes

For the next 3 years, Gretchen was under the auspices of AYI. The Core Services Team, which included among others Gretchen's parents, a case manager, and an apartment supervisor, was established and became actively involved in planning and reviewing Gretchen's placement, and treatment. Its reviews included frequent personal contacts with Gretchen, even during the two periods (one of them for 18 months) when she was in out-of-state placements.

Upon admission to AYI, a small co-ed group home near her home community was developed for Gretchen's treatment. It was run by highly experienced professional parents recruited for that purpose. Gretchen was placed with other adolescents. "In



the beginning, Gretchen was wild and running around, but she settled down and remained in that placement for 7 months, her longest continuous residence in 2 years," said her parole officer.

Gretchen attended high school and worked at a fast food restaurant downtown. During the summer, she spent a great deal of time downtown. She disliked the group home manager, said that he was rough with her, and not being home much was her way of dealing with him. She bought a new bicycle with her earnings and almost immediately had an "accident" with it, ruining it.

#### According to Gretchen:

I lived there 6 months. Every time I told people about him (the group home manager), they would send me back there. He used my past against me so no one would believe me. Then I'd go back and he would take it out on me. Basically, I only slept there. I got my job at Big Burger and hung out at the mall to stay away from the group home. I OD-ed once really bad at the mall and spent two weeks in the hospital. I hated life, hated the group home, hated everything.

Nevertheless, operating from her open residential setting, Gretchen functioned fairly successfully in the community throughout this period, and she attended high school during the school months. After nearly 7 months, however, the home was forced to close under a cloud of accusations. It was learned that the group home parents had misrepresented their background. This was compounded by allegations of abuse by Gretchen. After her suicide attempt, Gretchen stated:

I went back to the group home because I really liked my job. He screwed around and . . . I shut the group home down because he was a creep and he was messing around.

Gretchen had seven highly restrictive residential placements in the next 10 months, including a 3-month stay at a residential institution out of state. First she was sent to a psychiatric hospital for a month, then to her local community group home where she attacked a staff person with a knife. Next she was sent to a juvenile detention center. To get her there safely on a small plane, she had to be trussed up with plumber's tape and tied with ropes to prevent her from causing a serious accident or injury (i.e., to prevent her from physically attacking the pilot or opening the door or exit to throw herself out of the plane). She was taken to the secure juvenile detention center, then sent on to a psychiatric facility due to her self-abusive and violent behavior. She was then returned to the secure detention center for a month until a secure, out-of-state placement could be arranged. She returned from the out-of-state placement at the institution's insistence after only 3 months. The staff there were unable to contain her extremely self-abusive behavior and suicide attempts which were frequent and ongoing.



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She was then returned to the closed psychiatric facility followed by the secure juvenile detention center, once again.

During this 10-month period, 2½ years after her initial break with her family, an emotionally traumatic experience was indirectly disclosed. A letter Gretchen dropped was found by therapeutic staff. In it she disclosed that when she was 9 years old she had been sexually assaulted and then emotionally traumatized by witnessing a rape and brutal double murder by a resident of a low-income neighborhood not far from her home. She described how the man threatened to kill her while killing a cat, and later allegedly had her witness a brutal rape and murder of a homeless woman and her young son.

The existence of the man and his reputation were verified, but there was no information about the murders nor sufficient evidence to attempt to find and prosecute the man. This was the first time that anyone had heard anything of these traumatic events which allegedly had occurred over 7 years earlier. However, during the summer when she first began living on the street, a police officer had suspected and suggested sexual abuse as a cause for her changed behavior. None, however, could be confirmed at the high school where they suspected it must have occurred.

After further brief stays at the psychiatric hospital and juvenile detention centers, Gretchen was again sent out of state to a secure psychiatric residential placement. Here she remained for the next 18 months. Reports of treatment success during this placement were mixed. After receiving highly restrictive treatment to gain compliance (Gretchen lost all her privileges which meant living in a bare room with no furnishings or furniture), she began to cooperate with treatment. Here, for the first time, she began to discuss with her woman psychotherapist the earlier abusive events, she developed a close peer friendship with her roommate (her first close friendship), she completed her GED, and she reported that she personally felt safe and secure. She received one-on-one programming and both group and individual therapy. She had her own psychiatrist and psychotherapist. Throughout her stay there, she also received a heavy regimen of drug therapy. Some of the Core Services Team members felt that Gretchen made good progress in this placement; others felt that she was consistently and excessively over-medicated and was engaging in highly manipulative behavior.

After 18 months, plans were developed to return Gretchen to a community placement in her home state. She was included in this planning, although she also stated that she had no choice about returning and that she wanted to stay at this "school" which was like a college campus and where she had her own doctor, her own psychotherapist, friends, and activities, and where she felt safe. At the time of her release, the "school" reported that she had made good progress: she was down to an average of one 4-point restraint per month, had not sexually abused herself in 8 months, and had reduced her aggressive behavior.



When Gretchen returned from out of state, she was taking three psychotropic medications daily: antipsychotic, antidepressant, and anticonvulsant medications. Her drug therapy was discontinued upon her return.

As a transition, Gretchen lived with a specialized foster family for 1 month. She then moved to a supervised apartment in a building which included supervised apartments for persons with developmental disabilities. Gretchen participated actively in planning and buying for her apartment which she shared with a roommate who was developmentally delayed. She got a job at a store where she "accidentally" cut her hands while opening boxes. By the end of 1 month, Gretchen was demanding attention, yelling, and creating enough disturbances resulting in police responses, that the apartment program for other clients was deemed to be in jeopardy. She was then helped to obtain her own apartment in a location of her choosing where she received staff supervision and training, but where inappropriate efforts for attention were ignored.

Soon after moving into the second apartment and shortly after she had been refused voluntary admission to the psychiatric hospital, Gretchen created a huge scene in a nearby convenience store, breaking a plate-glass window and assaulting a police officer. She was arrested and put in jail where, once again, her behavior resulted in the use of 4-point restraint. She was then quickly sent to the psychiatric facility, which also had to employ 4-point restraint. Within a few days after it was determined that she was not an appropriate admission, she was sent back to jail. Shortly thereafter, she was released from jail and returned to her apartment where she received training and supervision a few hours per day if she requested it from supervised apartment staff. She also continued to receive psychotherapy from a woman therapist. It was at this point that Gretchen was interviewed for the AYI study. She had been living in the apartment for several weeks at the time of the interview.

Gretchen told the researchers wat the police released her from jail after they found out "the truth" about the incident when she had broken the plate-glass window and "had been raped." Gretchen's evaluation of the therapy services she had received through AYI were positive. She especially liked her female therapists, both her current one and her therapist at her "school." She didn't, however, like living alone in her apartment. She continued to catastrophize and to take no responsibility for her behavior whatsoever; she was still looking for someone else to save her.

At the time of the review, there appeared to be rather limited success in this case. Until very recently, the Core Services Team had relied heavily upon highly restrictive institutional services rather than finding ways to provide individualized wraparound community services. At the time of the interview, an individualized community effort was in place, although it had been in place only for 3½ months. Nevertheless, Gretchen was living independently in the community and was receiving AYI services



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on a voluntary basis. She was legally an adult and had been released from state custody upon her return to Alaska.

Up to the time of this study, Gretchen had completed her GED, had experienced a successful therapeutic relationship with a female therapist in her out-of-state placement, had experienced one good peer relationship which she planned to continue by mail, and had discovered that there were no more closed residential alternatives for her in Alaska to which she could resort, other than jail. She was continuing to receive AYI services, support for independent living, and therapy from a female therapist. Her program at the time of the interview required her to take responsibility for herself and for her own behavior while providing her with training and support in developing skills when she requested it. Her community adjustment at the time of this review was uncertain.

#### Evaluation: What Made It Work?

To the extent that individualized services worked, they incorporated the following positive features.

Continued Core Services Team commitment, coordination, and communication. The Core Services Team, which included Gretchen's parents, was involved in planning the two out-of-state placements. The team remained in contact by telephone conference calls with treatment staff at least every 3 months. Gretchen called her mother and her probation officer on a weekly basis throughout the 18 months of the second placement. Team members visited this placement and stayed in contact with each other and with Gretchen throughout her AYI tenure, regardless of treatment location.

Parent inclusion and support by AYI. The AYI Core Services Team included Gretchen's parents. Contact and coordination with them continued throughout her 3 years in AYI. Around the time of this study, the supervised apartment staff person brought Gretchen home to visit and to pick up materials for her apartment. This was very much appreciated by her parents. Until the visit, she had not been home of her own volition since the first time she ran away 5 years earlier.

Youth involvement in planning and decision making. Gretchen was included in planning for her return to Alaska and in planning and providing for her apartment. She was also put in charge of finding her most recent apartment.

Psychotherapy and personal support for sexual abuse. Having a supportive female therapist and a personal friend who was a "survivor" with whom she could discuss abusive experiences seemed to be critical to Gretchen.



Structured, supervised, responsibility training. Gretchen spent her longest period of time in an open community setting while living in the professional parent group home. The sudden dissolution of that resource precluded determining what response might have been obtained if such a placement could have been continued.

## Barriers To More Effective Services

Lack of services for unmanageable youth and their families. The inability to access help for their adolescent daughter during her initial 6 months as a runaway was an incredible frustration for Gretchen's parents. Since Gretchen had committed no crime, she was not eligible for any services. Her parents were extremely frustrated and distressed as she was living on the street and suicidal. They felt that they were viewed as being the problem, yet they received no assistance or support. They recounted that after her suicide attempt, Gretchen, age 14, was released by the hospital to two underage friends.

Short time frame in which to develop a community alternative with highly skilled staff. The short lead time and the need for very special foster parents resulted in an incomplete background check which eventually led to the untimely dissolution of the group treatment home. This situation indicates the need to be able to identify, develop, and maintain a reserve of trained and competent persons to serve as special teaching or foster parents for community placements.

Insufficient sensitivity to and early identification of signs of sexual abuse and other affective disturbances. Gretchen's parents were covertly blamed for Gretchen's anger and behavior disturbance. It was not until 2½ years after she began running that the story of her early trauma was uncovered. The school counselor admits that there were signs of emotional distress around the time of the alleged incidents, but that these signs were not pursued. School personnel need to be sensitive to, and rigorous in pursuing, issues related to abuse.

Lack of individualized response to maintain youth in the community. This was one case where the Core Services Team, under the auspices of AYI, chose to resort to a series of highly restrictive residential placements which eventually led to out-of-state residential treatment for a lengthy period of time. Although Gretchen had functioned in an open community setting for 7 months in a special group home developed for her, the Core Services Team was unable to put together a second structured, individualized community program for Gretchen upon the dissolution of the first one. Resorting to the available component programs led to 30 months of restrictive treatment. Upon her return to the community, Gretchen appeared to be no further ahead than when she left. Lack of availability of trained and experienced



personnel with whom to build an individualized program led to a return to traditional responses. This, in turn, led to traditional outcomes.

#### Conclusions

Gretchen, a redheaded 19-year-old woman, came from a middle-class family in a small town in Alaska. Her background did not appear to be unusual, nor were any particular problems identified during her childhood. Suddenly, however, at the end of seventh grade, she was identified as being despondent and suicidal by the school personnel. She began receiving counseling at school and, shortly thereafter, ran away from home at age 14. She never voluntarily went back home overnight after that time. For the next 2 years, Gretchen cycled between two psychiatric hospitals, a general hospital, and several community group homes. Her violent and self-abusive behavior often resulted in long periods of 4-point restraint. She ate broken light bulbs, jammed broken glass into her vagina, and repeatedly both threatened and attempted suicide. It wasn't until more than 2 years later that Gretchen divulged that she had been sexually assaulted and had also witnessed a brutal rape and, possibly, a murder when she was 9 years old.

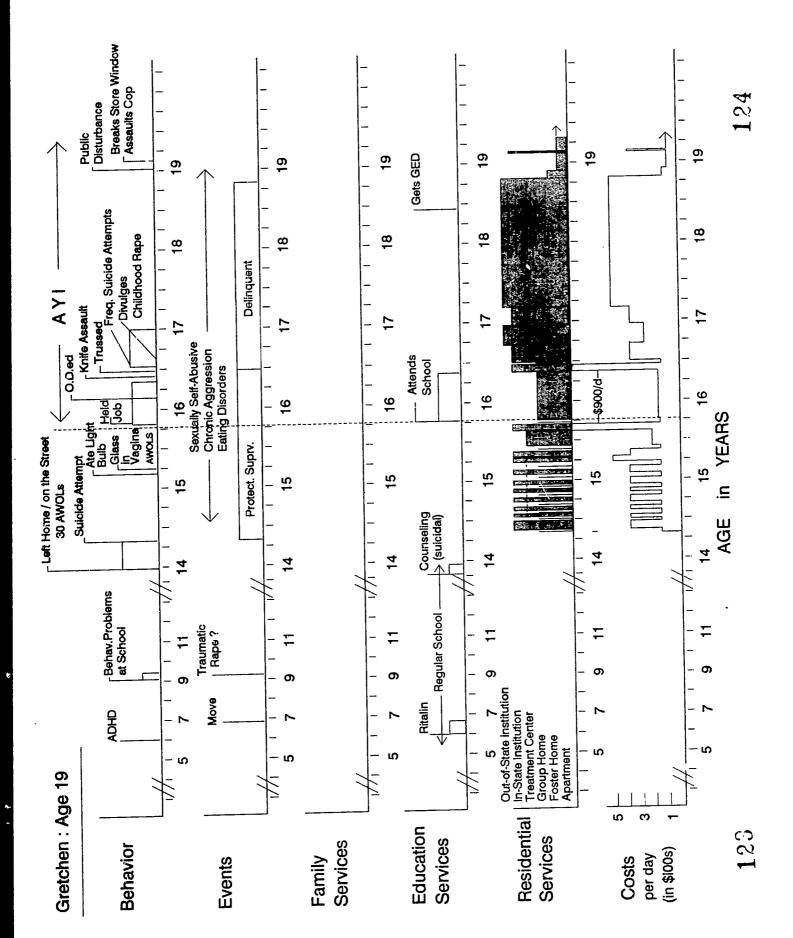
When Gretchen entered AYI at age 16, she was angry, depressed, self-destructive, sexually self-abusive, violent, paranoid, manipulative, highly accident prone, and had an eating disorder. For the next 7 months, Gretchen functioned fairly successfully in an open community placement, a small, professionally staffed group home developed specifically for her. This abruptly ended when the home was closed amidst allegations of abuse. Over the next 30 months, Gretchen was placed in eight restrictive placements, six in Alaska, and two out-of-state, extremely costly institutions.

Just prior to her 19th birthday, AYI brought Gretchen back to Alaska and to the community. She spent her first month successfully in a specialized foster home, then moved into a shared, supervised apartment for a month, and then into her own apartment where she received on-call assistance for a month. During the latter two months she kept demanding to be put into a psychiatric hospital. When she could not gain voluntary admission, she broke up a convenience store and assaulted a policeman. She cycled between jail and hospital in 4-point restraints for the next several weeks. At the time of this study, she was again living in her apartment with drop-in staff supervision. Her adjustment seemed quite tenuous. During her AYI tenure, she had completed her GED, entered a successful therapeutic relationship that was helping her deal with issues related to her traumatic sexual abuse, and developed one peer friendship. Staff were attempting to assist her to begin to take responsibility for herself. She continued having accidents and demanding attention at the time of the review.



A summary of the major events in this case: familial, educational, mental health and residential services received, service costs, and behavioral events and episodes are displayed on multiaxial timelines on the next page.

Sources of Information: Information for this case study was obtained from a review of case records and from personal interviews with Gretchen, her mother, her probation officer, the AYI case manager, the AYI regional coordinator, two case managers at the psychiatric hospital, staff at the correctional center, and AYI central office staff.



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## CHAPTER 7

# Conduct Disorder: Three Individuals, Three Individualized Responses

This chapter presents the stories of three different youth who were labeled conduct disorder: a young boy and two young women. These youth were similar in expressing acting-out, aggressive, and unmanageable behavior. They were different in the manner of its expression, different in the familial-social contexts from which they came, and different in the manner in which AYI individualized the wraparound services they received in the community.

The first case involves an 8-year-old boy just before his first institutionalization was to take place. The next two stories are about two women who came into AYI after multiple institutionalizations.

## Case: Ned - Conduct Disorder in the Making

Ned Downs was an engaging, self-assured elementary school child. He was very active and curious about everything. By age 7, he was already a "tough guy," with a real tough guy self-image. He freely used sophisticated drug and street talk with the other second graders and teachers. He was aggressive and verbally abusive. He stole money from teachers and students, and, according to his teacher, "was mean as hell." Six weeks after beginning second grade, he was labeled seriously emotionally disturbed (SED) and was placed in a segregated classroom with four other children also labeled SED. This class had a teacher, an aide, and a "guard" to assist in putting the children into the time-out room when necessary. Ned called the guard a "gorilla." "She's a beast! She takes us down and then picks us right up off the floor and carries us to time-out. I hate her."

After a few months in this special classroom, Ned destroyed the time-out room. He did such a thorough job that the segregated class had to close for 3 days while the room was repaired. Later, Ned broke a teacher's nose as he was being physically "helped" back into school from the playground where he was picking fights with the other boys. Ned proudly described how he "got him with a Ninja kick." Ned was very proud of how tough he was, that he was able to break a teacher's nose; but he was even prouder



of another kid in his class, Joey. "Joey is a really tough kid, even tougher than me. Joey is really wild and terrible." All of this was said with admiration and awe in his voice.

Ned was suspended from school near the end of second grade. He was considered hyperactive, oppositional, defiant, and aggressive; a conduct disorder with a great future career as a delinquent and criminal. He was under active consideration for an institutional placement, his age was 8.

## Background

Ned's parents had their first child, Ned's older brother Tim, when they were both 15 years old. They had Ned 7 years later, and were divorced a few months afterward. The court awarded the children to Ned's father, as his mother was heavily involved with drugs. She left the area and, although she occasionally corresponded or called the children usually to tell them that she would come and rescue them, Ned never met her until his sixth birthday; and then he saw her only for a few short hours.

Ned and Tim lived with their dad and stepmother in their home community where the extended Downs family was well known. This extended family was reputed to have many connections to criminal elements in the community and many members in need of social and mental health services. After the divorce, Ned and Tim lived with their dad and stepmother for 5 years, until Ned was 5½, when they were removed from the home by Children's Services for neglect and abuse. The brothers reported that during this period they were frequently left at home alone, locked in closets and bedrooms to keep them safe while the adults were gone, sometimes for days at a time. Tim remembered that when they were locked in the closet, they often were in urine-soaked clothing. One time when he and Ned tried to escape out a bedroom window, Ned fell and hurt his arm. Their dad solved that problem by nailing the window shut. Tim had very strong, nurturent feelings toward his younger brother. "I raised him for the first 5 years, until we were placed with Aunt Ruth."

The two children were then placed with elderly relatives in the same community. Ned never forgave these relatives for "breaking up my home," nor did he forgive Children's Services. He was sure that Children's Services and his Aunt Ruth conspired to have his mother sent away, broke up his home, and kept him from being with his dad. At the time of this study, he still felt that way.

The children stayed with their maternal relatives for the next 9 months. After 3 months, Ned entered ki dergarten where his behavior was reported as unmanageable. The relatives reported that they were unprepared for the anger and disturbance that the children displayed and felt totally at a loss. They received no support or assistance

which they sorely needed for dealing with the children. During the last 4 months of their stay with these relatives, the children, along with their father and stepmother, received family counseling. After they were placed back with their father and stepmother, the family received homemaker services as well as help with budgeting and nutrition. They also received respite services.

Ned and Tim lived with their father for the next 1½ years until he was arrested on drug charges. During that period, Ned's father moved him to a new elementary school. Mr. Downs was furious with the former school for reporting him for suspected child abuse. In the new school, Ned continued to have extreme behavioral difficulties. School personnel reported that Ned was in and out of school repeatedly during the first grade as his father was continually moving his residence around the community.

After his arrest, Ned's father called Aunt Ruth and asked her to take the children back. During the second 9-month period when they had the two children, the relatives again reported that there were no services or assistance available to them with respect to how to manage or help the children; nor was there any real respite. Although some respite was provided, the children were taken out one at a time so that the elderly couple had virtually no time without child supervision responsibilities during that long period. Ned became increasingly unmanageable. He engaged in compulsive stealing; he took money, several checks which he managed to get cashed, a rhinestone necklace which his aunt thought he sold to neighborhood children, and other items. Even the cat's scratching post mysteriously and permanently disappeared from the home.

Ned was unmanageable at home and at school. It was during this period, second grade, that he was placed in the segregated classroom for seriously disturbed children, tore up the time-out room, broke a teacher's nose, and was suspended from school. He picked fights on the school bus, and was especially belligerent and intolerable right before and immediately after any contact with his father. After 9 months, the elderly couple could no longer cope with the children. They called Ned's father in great distress and demanded that he take the children back.

Ned and Tim returned to live with their father for the summer months while their father was awaiting sentencing and while the school and Children's Services attempted to determine what could be done with and for Ned and Tim. While they identified a foster placement for Tim, they were investigating a restrictive residential and educational placement for Ned, age 8, who was about to enter the third grade, far from his home community. He already had a 3-year history of being physically and verbally aggressive, abusive, unmanageable, oppositional, defiant, and hyperactive; and, he was a compulsive thief. A referral was made at this time to Alaska Youth Initiative.



#### Alaska Youth Initiative: Services and Outcomes

A Core Services Team was established to plan and coordinate services for Ned. The team included representation from Children's Services, the school, special education services, a guardian ad litem, the AYI coordinator, and Ned's father. The team met at least every 3 months. After the initial start-up, the maternal aunt and uncle and the special foster parent also became members of the team and participated regularly.

A shared-care residential apartment was created for Ned so that he would be able to begin school in September with a coordinated home and school program in place while special foster parents were located and trained. Several trained women workers experienced in using behavior management and working in developmental disabilities services shared the residential supervision, school coordination, and behavioral programming for Ned. They lived with Ned in an apartment for a month while AYI looked for, found, and employed a trained and experienced woman as a specialized foster parent. AYI funded a taxi so that, from his new residence, Ned could continue to attend the same elementary school.

The specialized foster parent was a former health club instructor who had worked in a community program for persons with developmental disabilities. She was trained and experienced in the use of behavior management strategies and in social skills training methods to provide structure, instruction, and reinforcement for socially appropriate behavior. A thorough-going behavior plan was developed and implemented at home that incorporated results from the daily notes from school and the bus with the behaviors expected at home.

All house rules, behaviors, and expectations were clearly spelled out and put onto a daily point card for Ned to keep. This was then transferred onto a weekly point sheet for Ned to see. Ned earned points for basic and special privileges by completing assigned tasks and acting responsibly in very clearly specified ways. Unacceptable behaviors (e.g., breaking things, swearing, hitting people or animals, or running away), earned negative points (or, in effect, resulted in point loss). However, there were many ways in which to earn points. Expected activities included helping to care for the domestic pets, house chores, displaying appropriate table manners, and adopting other social behaviors such as accepting "no" for an answer, disagreeing appropriately, taking criticism, asking permission for specified activities, carrying out independent and timely self-care (i.e., eating breakfast, taking baths, preparing for bedtime), and completing homework.

AYI also employed a special male aide to accompany Ned at school for the first several months. He put Ned on a token program and attempted to mainstream him for much of his school time. Consultation and coordination between Ned's foster parent and his special education teacher were close, continuous, and daily. They often had multiple



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daily contacts by phone and note, and the foster parent was continuously on call to come and pick Ned up and take him home whenever the school requested, contingent upon his behavior. Ned was provided with a child therapist at the local community mental health center whom he has seen regularly since that time. A male respite worker also was employed to provide out-of-home activities for Ned. According to Ned, this involved taking walks, hikes, skiing, and playing video games, which he enjoyed. He thought his adult male respite worker was "cool."

By the end of that year, third grade, Ned's school performance had changed dramatically. He was receiving very good grades, was entirely mainstreamed at school, was completing 80% of his assignments successfully, and his aide was functioning as an aide for all of the youngsters in his class. He was polite in assembly, asking appropriate questions, and behaving appropriately on the playground rather than precipitating fights. He still became upset around the times when he visited with his father in jail, having to be restrained several times physically, and becoming resistant to following instructions and taking on the "tough guy" role once more. These issues, however, were limited to a few days around each visit. In the school's February assembly, Ned received a gold medal for reading, he participated in the after-school soccer program, the latchkey program, and a community service program at the police station. His school performance was characterized as the difference between right and day during third grade.

Ned's remarkable progress continued during the summer. He went with his foster parents to a summer home (the foster father, often away due to his work, was home all summer). He attended the community day camp recreation program for children on a daily basis with no additional supervision nor with any identification of him as a child who needed special supervision or one who had special problems. Ned's foster father was a police officer who provided him with a highly masculine and socialized role model. At the time of this evaluation, Ned's "tough guy" image had been posivively influenced by his strong identification with this foster father.

#### Evaluation: What Made It Work?

Ned made a very dramatic turnaround according to his school principal and other informants. The principal attributed this change to the closely coordinated services with which he had been provided throughout that school year under AYI. Prior to AYI entry, the school personnel saw no way to maintain Ned in their school and they were prepared to send him away. They were extremely impressed at the rapid change he made. Ned was very positive about his special education teacher, his mainstream teacher, and his foster parents, and he was proud to have received good grades and awards at school. He was still angry, however, with his relatives and with Children's



Services, whom he held responsible for breaking up his family. He was fond of his brother, whom he was able to see from time to time, and felt strongly about his father, although he would not talk about him.

The features of the AYI individualized program which were seen as major factors in this rapid and dramatic turnaround were as follows:

Effective interagency coordination, cooperation, and planning. This was achieved by a Core Services Team which included all essential participants: education, children's services, mental health, advocacy, Ned's father, custodial relatives, and foster parents.

Flexibility and individualization of programming. Examples of flexibility and individualization included the provision of a shared-care apartment as an immediate first measure until other, more permanent, arrangements could be made; funding transportation so that school coordination and placement would be uninterrupted; and providing a classroom aide, as needed, to support school services.

The ability to recruit well-trained, highly skilled residential service providers. This occurred first in the shared-care apartment and then, most critically, in the foster home. The foster mother was especially skilled in the administration of structured behavioral techniques which helped Ned to achieve good behavioral control and improved social skills. Her positive rapport with Ned testified to her positive approach to the training.

Close and effective home-school coordination and cooperation. The foster mother was virtually "on call" as a back up to the school and communicated with the school on a daily basis.

Unconditional care. Ned's specialized foster parents supplemented their professional skills with important interpersonal skills and personal concern for Ned. They demonstrated genuine, ongoing interest in his development as a person, and provided him with strong, positive role models.

Stable individual care versus group care. Ned was provided with a firm, continued, stable, supportive residence away from other children with demanding emotional problems.

Implementation of a structured, behavioral program. A well-designed, clear, and comprehensive behavioral program was introduced to teach and support positive social behaviors and responsibility both at home and at school.

Timely development and implementation of the Core Services Team plan. The ability to introduce resources into the community in a timely fashion prevented



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school officials from activating their initial plan to send Ned to an out-of-state residential program.

## Barriers To More Effective Services

Issues identified by respondents with respect to some of the barriers to the operation of the individualized care program included the following:

Lack of stable employment and benefits for staff. Employing people for individualized and often temporary services precludes the usual expectations of permanent work in a career field. Development of career ladders and opportunities for job security is a challenge that needs greater attention.

Insufficient professional consultation and support. Consultation and assistance for behavior management and clinical issues at home and in school, especially in the initial phase, would have been beneficial in this case.

Insufficient mediation between natural families and foster parents. There was a need for more supportive mediation between natural family members and specialized foster parents to improve communication and mutual understanding.

Inability to resolve the ultimate dilemma. When the family social environment has been a major contributor to a youth's maladjustment, the goal of serving the youth in his or her family and community may conflict with the need to provide the youth with a stable, continuous, constructive, and caring home. Ned progressed in a very stable and supportive, middle-class family. The social values, expectations, and opportunities in this home conflict with those of his home of origin. If Ned is returned to his original home environment, it is difficult to see how he could continue to make progress in socialization and in essential academic achievement (i.e., how could he help but revert to his negative, "tough guy" mentality and role?). It does not seem reasonable that providing 1 or 2 years of heavy service will inoculate a youngster such as Ned against the pervasive, negative environmental influences surrounding his natural home environment. If he doesn't stay with his present foster parents, how can Ned experience the stability and reinforcement necessary to develop values and skills to survive out of jail and out of trouble?

Other important service issues related to the education of youth receiving AYI-type services were identified as follows:

According to a school administrator, a significant number of service providers
and educators believe it is cheaper and more effective to send kids out of state
than to serve them in the community.



- There is a need for early intervention and family support as soon as the school sees problems. The school's initial response to this family's needs was too slow.
- Children's Services and the schools need to work closer together. Family service workers should have offices in the public schools. Also, the resources of Children's Services are too limited to be effective.

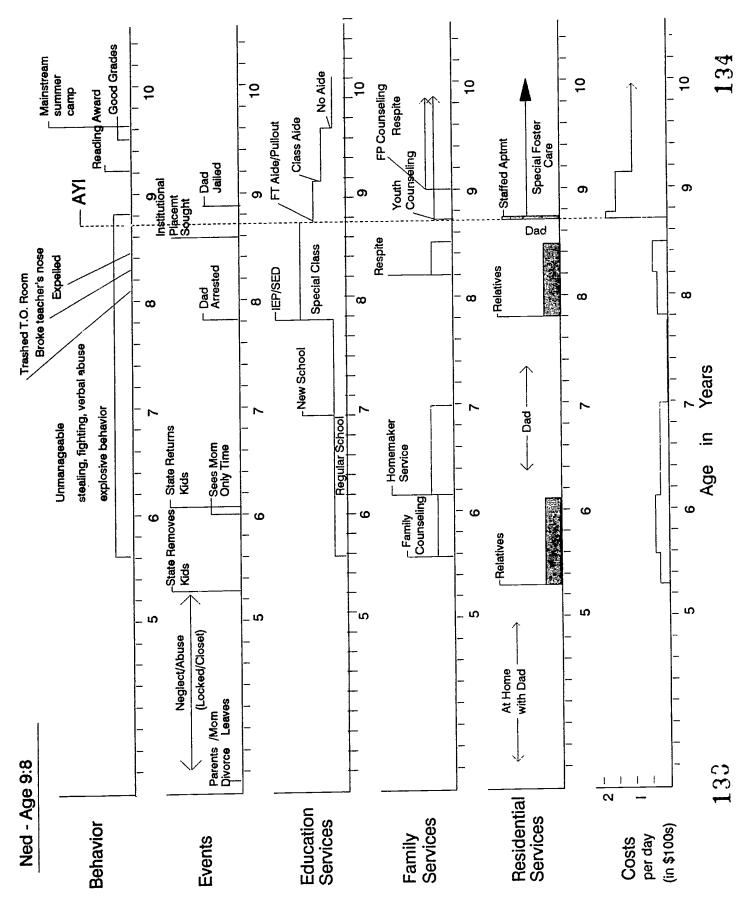
#### Conclusions

Ned, an 8-year-old "tough guy," already exhibiting highly aggressive, disordered behavior and labeled seriously emotionally disturbed by the schools, was in line for restrictive, out-of-community residential placement. Ned's case is an example of intervention done earlier than most of the other AYI cases. AYI came into this situation before the youth had experienced a large number of out-of-home placements and at a much earlier age than most of AYI's other referrals. Ned received intensive, pervasive, coordinated support in his home community in a family setting and in his school. In only one year, Ned's AYI experience had a dramatic effect on his behavior and adjustment. All informants were in agreement that he had improved markedly and dramatically in interpersonal behavior, in control of verbal and physical aggression, in use of appropriate speech, in academic performance, and in adopting appropriate socialization role models.

This case exemplifies the potential power of a highly structured, coordinated, wraparound intervention in a family and neighborhood school setting when the intervention is early in the potential career of a child experiencing severe environmental and personal stress and emotional disturbance. The specifics of the major events, behavioral responses, services, costs, and outcomes are seen in the timelines displayed on the next page.

Sources of Information: Information for this case was obtained by reviewing case records and by conducting separate personal interviews with the principal of Ned's elementary school, his two AYI specialized foster parents, his aunt and brother, his Children's Services social worker, the AYI case and regional coordinator, AYI central staff, and Ned.





## Case: Carol - The Story of a Drug-Addicted Prostitute

Carol spent the first 13 years of her life with her family in extreme isolation on a remote, inaccessible homestead, attending school by home study and correspondence courses. By age 15, after moving to an urban community, in less than a year and a half, Carol was a drug addict and a "highly successful" prostitute. She presented herself as a gorgeous, sophisticated 19-year-old woman and was making over \$100,000 a year for her pimp. In addition to being a highly paid prostitute, she was mainlining heroine and cocaine, dealing in drugs, and dancing and stripping in a club in a nearby large city.

Carol's primary presenting problem was conduct disorder coupled with drug addiction. By mid-adolescence, she had managed to run away from every type of placement and residential treatment facility, including closed juvenile detention and treatment centers. She had engaged in suicide gestures, was unmanageable and incorrigible, had assaulted police and social service staff, and supported herself financially through drugs and prostitution.

## Background

Carol was described by many informants as an extremely attractive, in fact, a "gorgeous" woman. She also was described as very intelligent. She had been born to a drug-addicted mother, the youngest of several children. The family moved to a remote homestead with their father and new stepmother when Carol was 1½ years old. As mentioned before, the family lived in isolation throughout most of Carol's first 13 years, the children receiving their education by correspondence courses. Retrospective social service reports indicate that Carol's father traveled extensively and was gone from the home much of the time. Carol, her brothers and sisters, and her stepmother quarreled and fought constantly. Carol also reported that during this period, she was physically, emotionally, and sexually abused by her stepmother and sexually abused by her brothers. Carol's father, also reporting retrospectively, said that Carol was an alcoholic by age 9.

The first contact with social services was made by her father when Carol was age 6. He went to the nearest town, which was over 50 miles from the homestead, and requested help from a local counseling service for marital problems. He proceeded to describe his daughter as so unmanageable that his wife was threatening to leave him. He did not, however, follow up and obtain any family services. A year and a half later when Carol was 7.5, her father called the agency and requested that they find a foster placement for his daughter "to show her." He described her as "barbaric," saying that she "was trouble from the start, unmanageable, and destructive," and that she "stole, cheated, lied, and attempted to run away from home."



Social workers went to the isolated homestead by snowmobile, the only way to get there in mid-winter. Following their investigation, they removed Carol and placed her in a foster home in town for the 4 remaining months of the school term (i.e., first grade for Carol). During this period, Carol's behavior was considered normal by the foster parents and social workers. However, during this time Carol reported that a school friend's father had attempted to engage her sexually. At the end of the school term, Carol returned to her family in the bush where she remained for the next 5 years.

The next official family contact with human services was when Carol was 13. State officials flew by helicopter to the family homestead to investigate a report by an itinerant miner that the children were being severely physically abused. He had seen them locked up in a shed for many days without being fed. The children were removed and placed in foster homes in the nearest town. The family then moved to town for the summer and Carol was returned to her family. The family, however, moved back to the homestead for the nine long winter months, and then back to town the next summer. By the middle of the second summer, Carol's father wanted to "give" Carol to state social services as she was so incorrigible. She had run away from home on several occasions, had stolen his truck, and had ruined it in an attempt to drive out of Alaska.

After having spent all but 4 months of her first grade and the summer of her 13th year in isolation with her family, Carol, now back in the community, was sexually active, on drugs, and practicing "witchcraft." Social services staff declared her a child in need of supervision. She was placed in state custody where she began a 2-year odyssey of travel through every type of available placement and onto the streets for long periods of time until she was finally incarcerated in a juvenile jail. She managed to escape from this jail on two occasions.

During her first year in the child welfare system, Carol had four failed foster placements and spent most of her time living on the streets, engaging in prostitution, heavy drug use (marijuana, alcohol, speed, and intravenous cocaine and heroin), and public sexual promiscuity (she vas repeatedly apprehended in the bathroom of a public recreation facility sexually engaged with men). Her father then took her at gunpoint from her pimp and put her in an out-of-state 35-day drug rehabilitation program. From this program, now age 15, she was sent to placements in a region of Alaska distant from her home. First, she was sent to a group home from which she ran away 6 times in 3 months, assaulted a staff member, was arrested, assaulted a police officer, and was sent to a locked detention center for 1 month. Then, Carol was returned to her home community to a detention facility, was released to a foster placement, and promptly ran away. She spent the next 6 months on the streets engaged in shoplifting, prostitution, and drug dealing, appearing in a distant town as a stripper, and making very large sums



of money for her pimp. Finally, she was apprehended and returned to the detention facility in her home town the summer of her 16th birthday. She was placed in a group home from which she ran away twice and was then placed in a closed youth facility for delinquents where she remained for 1½ years.

In closed institutional settings, Carol was reported to perform well but was unmanageable and incorrigible in community placements. Whenever she was able to leave the institution (AWOL and on a pre-release pass), she took up with her pimp and got heavily reinvolved in drugs. According to a corrections official, "Carol still sees prostitution as a safe and useful career."

At age 17, social service and probation officials were attempting to find a way to reintroduce Carol safely and successfully to community living. Although her father would appear once or twice a year to see Carol, no one ever knew where he was or how to contact him, including Carol. Carol did not want to be in a family situation again and wanted to be independent in the community. However, she had reportedly witnessed a murder during one of her unapproved absences from the juvenile facility and had her life threatened. She had become afraid of leaving the safety of the institution. During a pre-release pass, she reported that she had been abducted and raped by a rival pimp. She was also sure that her pimp would be waiting to whisk her away from the gates of the juvenile detention center when she was released.

After a 2-year career running away from all available programs and living primarily on the streets, followed by 1½ years in a locked institution, Carol was released to the AYI program at age 17½ for community placement.

## Alaska Youth Initiative: Services and Outcomes

According to a treatment team member, when Carol entered AYI she was a keg of four-letter words and was dressed like a prostitute. While in the program, however:

She learned how to dress, how to act. Her change in appearance was incredible, and it persisted. She developed a new set of values. She became really proud of herself. She wanted to impress her case manager. She kept her table set like in a restaurant . . . invited friends over for full-course meals which she fixed from beginning to end. She became very, very responsible, made and kept her own appointments, got her own groceries, [and] began to set goals for herself . . . There were changes in her personality, she became more sociable . . . She enjoyed and appreciated a different standard of living . . . By the end, she'd stopped doing four-letter words.

Carol was in the AYI program for 15 months from age 17:5 to 18:8. She was made a part of the Core Services Team and the planning process from the start. Upon release



from the youth facility, she was placed in a 24-hour staffed apartment in the community and was made to feel that this was *her* apartment. She helped select it, helped purchase the furnishings, and interviewed and helped select the staff who were to be hired to provide supervision.

At first, the apartment was made very secure due to concerns about intrusions from criminal elements from her past dealings in drugs, prostitution, and related criminal activities. The area around the apartment building was well lighted and police were alerted to be vigilant; they made extra patrols and were prepared to respond to phone requests for assistance.

When Carol first entered the staffed apartment, she had 24-hour staff supervision, 7 days a week. Soon she was able to earn time alone in her apartment; eventually she earned weekends without staff. She also was given increasing amounts of time when she could be off premises independently as long as she followed guidelines, called in periodically, and came home on time. One staff person, who was a former model and very glamorous, assisted Carol in learning how to dress and use makeup, she served as a valuable role model. According to one team member, "The staff and Core Services Team members treated Carol like a lady."

Carol never ran away from this community placement. She completed her GED, worked part time, learned a variety of independent living skills, such as cooking, appropriate dressing and social skills, and she began changing her peer group. Drug testing was done periodically; she had one incident of documented drug use (cocaine) early in the program. As a result, she entered a Narcotics Anonymous program and made progress through many of the steps. She honored her curfew and stayed out late only one time when she got drunk and called for assistance in getting home. For the rest of the time, she appeared free of drugs and followed apartment rules. She learned computer entry skills and demonstrated an exceptionally good work ethic and excellent work skills at a job held briefly (3 weeks) at a local community agency.

After 4 months in the AYI program, Carol secretly married a former boyfriend. She announced this to staff a few months later when she turned 18. Her husband was made a member of the Core Services Team and he was allowed to be in the apartment over the weekends with staff on call and checking in at times. After a few months, however, he went to prison for a prior felony. By this time, after 10 months in the community, Carol was pregnant. Initially, plans had been made for Carol to exit AYI by the end of her first year. However, with her husband in prison and with her pregnant, Carol negotiated a behavior contract with AYI to continue residing in an independent living apartment. She wanted continued financial assistance and support until she could receive AFDC. She had to stop working at a retail store due to her pregnancy. She was unable to stand for long periods of time as she had injured her



ankles and feet by using them as sites for intervenous drug injections during her adolescence.

During the 3-month period in the independent living apartment, Carol received 3 to 4 hours of training daily and she attended parenting classes, but her compliance with her behavior contract gradually decreased and her contact with former street friends increased. She then received an ultimatum from AYI staff that said she had to comply with her contract or be evicted. A few days later, she left the apartment without notice and moved to another city. By this time, she had begun receiving AFDC payments. Shortly thereafter, she contacted AYI staff and AYI services were discontinued.

At the time of this study, Carol was continuing to maintain contact with her AYI case manager and staff person. She had her baby in the summer, appearing to remain drug free during her pregnancy and post-partum period, and stated that she had not engaged in any prostitution as a means of self-support in the 18 months she had been in the community. She was traveling to visit her husband in jail and was maintaining an apartment with her baby. Staff felt that Carol had met her initial personal goals. As one team member put it:

She wanted to become a mother, wanted to graduate from high school, and wanted a place of her own. She talked about being a "good mom" with a good relationship with her children. She wanted to be away from her former street buddies and alone so that she could focus on her own life.

All informants agreed that they saw Carol make great progress during her 15 months in AYI and that the experience made a tremendous impact on her life. Carol changed her lifestyle, developed a new set of values, began to set goals for herself, and changed her personality. She learned self-respect, how to dress, how to act (no longer was she "a keg of 4-letter words"), and she learned independence skills so that she could live without prostitution or drug dealing. She became responsible and independent, making and keeping all her own appointments. She did all her own shopping and cooking without prompts, and took great care of her apartment. When she completed her GED, she did extremely well on the test. She became a good mother. She wanted to be in control of her life rather than being controlled by others as she had been. Carol seemed to have achieved these goals, at least temporarily.

Since AYI termination, Carol relocated to another city, in part to cut loose from her old crowd of street friends. She continued to have good relationships with several team members. Her remarkable change in appearance persisted. During her pregnancy, she followed good prenatal care and, from reports, she continued to be drug free.



#### Evaluation: What Made It Work?

The factors which the respondents identified as contributing to Carol's successful experience in AYI include the following:

Carol's active participation in the Core Services Team. Carol interviewed applicants for staff positions to work with her, picked out her own apartment, selected the furnishings, and participated actively as a team member in planning and developing her treatment program.

Staff commitment and personal skills. AYI staff had the commitment to hang in there with Carol, no matter what. They had immense dignity and brought skills and a personal style that enabled Carol to develop significant, respectful, trusting relationships with them. Staff provided excellent role models for Carol, especially the one who was a model and showed Carol how to dress, talk, act, and present herself.

Individualization of the program. Being able to design a program around Carol, being flexible, being able to alter the program substantially based upon her current and changing needs, being able to provide the program that the Core Services Team (including Carol) wanted was critical to the success of this case.

Staff consistency in using structured program. Using a structured program to teach limits and responsibility, having consistent in-house rules that were supported by staff and by the Core Services Team, and having good communication among staff and team members also were important factors in determining the outcome of this case.

Core Services Team coordination, communication, and cooperation. Core Services Team meetings were held frequently and helped promote both communication and consistency. Direct care staff and the client were included and were listened to. All came, all participated; there was good interagency cooperation. The team process was regarded as excellent by all who participated.

Staff supervision and support. Direct-care staff supervision was excellent. There were weekly supervision meetings and daily communication among staff, members. Supervisors were always available to do anything staff needed, answer any questions, or just listen. They were respectful and appreciative of staff, and staff had substantial input into all phases of development and acting out the treatment plan.

Client tracking system. The weekly client tracking report was seen as valuable by coordinators. It helped to avoid potential crises over weekends, it provided a good view of the client at any time, and it helped prevent staff burnout. The recorder met all informants (this staff member was not a faceless person), attended all meetings, and provided a monthly summary to each informant.

## Barriers To More Effective Services

The major limitation in Carol's AYI program identified by this evaluation was the timeliness of the intervention. She should have been reached earlier so as to have had more time to develop skills and healthy social relationships. She and her new daughter are high risk, despite her new skills and attitudes.

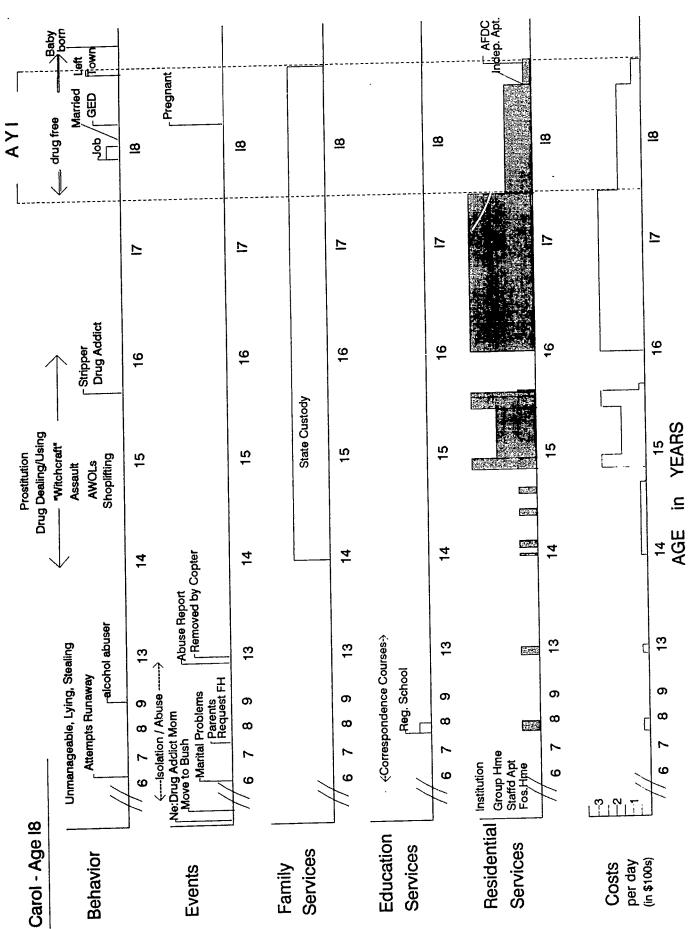
#### Conclusions

Carol at age 14, after 13 years of living with her family at an isolated homestead and experiencing severe and continuing family conflict, including physical, emotional, and sexual abuse, was on the street, attractive, and looking 19. By age 15, she was a highly successful prostitute, a serious intervenous drug user, and making huge sums of money for pimps. By age 16, she had spent nearly 2 years on the street, having been in and out of seven different placements. She then spent the next 1½ years in a secure youth correctional facility. She was released to AYI. During the next 15 months in AYI in a supervised and independent living apartment, Carol made remarkable improvement. She obtained her GED and learned valuable independent living and work skills that enabled her to support herself without resorting to prostitution. She married, gave birth to a daughter, and is currently living on AFDC payments. Although Carol remains a person at risk with a child at risk, her positive response to AYI services was attributed to: (a) the consistency and follow through of the program structure; (b) the quality of staff working with her (the relationships they were able to develop, the role modeling they were able to provide); (c) excellent staff supervision and support; (d) the flexibility inherent in the AYI program in terms of having flexible funding and providing individualized programming; (e) the effective team process which included Carol, her direct-care staff, and was characterized by excellent and frequent communication and effective listening, and (f) the excellent interagency cooperation that the team was able to obtain.

The factual events in this case are represented on the following page which shows concurrent timelines that summarize Carol's behavioral history, major life events, and the educational, mental health, and residential services she received, as well as their costs.

Sources of Information: Information for this case study was obtained from a review of records and from interviews with Carol's probation officer, AYI case manager, AYI regional coordinator, and AYI independent living supervisor who was also one of Carol's supervised apartment direct-care staff. Attempts to contact Carol for an interview were unsuccessful as she was out of the region, moved several times during the 2-month period of this study, and was away visiting her susband when her residence was located.





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## Case: Jill - Rebel With a Cause?

Jill Smith's psychiatric records read: "Rebellious, highly aggressive, assaultive, unmanageable, oppositional, manipulative, and suicidal." Her diagnoses included, "conduct disorder, borderline personality, and suspicion of multiple personality."

This is the description of a petite, energetic, verbally fluent, 15-year-old girl who, in less than 3 years, had in excess of 18 failed residential placements and over 20 school suspensions following removal from her home. She lived in an isolated rural setting with an elderly, widowed, adoptive father. Although her adoptive father was totally committed to her care and upbringing, her relationship with him was characterized by a close relative as, "Jill runs over the top of him with track shoes."

Jill was removed from her home at age 12½ for unmanageability. She told her father, "Man, wouldn't it be nice to have two parents?" and her counselor, "I wish I could live with a mother and a father who had other kids instead of with one old man." Subsequent to her removal, Jill engaged in a 3-year sojourn back and forth, in, out, and through the entire available continuum of mental health and juvenile service programs: foster homes, a youth shelter, group homes, a secure youth detention facility, an intensive youth treatment center, and psychiatric hospitals. The numerous psychiatric and psychological evaluations she acquired as she bounced from one program to another all concurred that Jill was suicidal, highly aggressive, assaultive, extremely dangerous to other people, and required long-term, locked, psychiatric care. She was 15 at the time. It was then that she came to the attention of AYI.

## Background

Jill's biological parents were divorced when she was 2 years old after her mother was prosecuted for cashing bad checks. Her father is said to have told her mother after her arrest, "You are unfit to be a mother." Jill and an older sister lived with their father, stepmother, and several step-siblings until Jill was 9. By this time, Jill's stepmother was having great difficulty in controlling Jill, who was hyperactive, aggressive, and manipulative. In order to get respite, the stepmother sent Jill to visit some friends of hers and then refused to allow her to come back home. The friends, an elderly couple who had already raised their own family, kept Jill and adopted her. A few months later, however, before her 10th birthday, Jill's adoptive mother died suddenly in a traffic accident. Mr. Smith, although he had great difficulty controlling Jill following his wife's death, assumed his wife's commitment to provide a home for Jill.

During the next two years, Jill's rebellious, demanding, and wild behavior led Mr. Smith to take her to a mental health clinic. With incredible rapidity, Jill was able to change from a raging, emotionally upset pre-adolescent to a very sweet, cooperative,



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and rational child. To some mental health professionals she had a multiple personality disorder. One psychological evaluation, however, refuted this notion and attributed her unpredictable, highly unmodulated behavior with abrupt and intense mood swings to manipulation; it was her way to control the adults in her environment. She had developed a repertoire of diverse strategies which she employed to obtain her way.

By the time Jill was 12½ years old, Mr. Smith decided that her rebellious, oppositional, and unpredictable behavior had increased beyond his tolerance, and he took Jill to a local center for family counseling. During 4 months of counseling, it was determined that Jill, her sister, and her stepbrothers had all been subjected to continual sexual, physical, and emotional abuse from her biological father. During her first 9 years, Jill had been locked in trunks, locked in closets, threatened, beaten, and sexually abused. Due to her continued unmanageable behavior and her expressed wish to live in a real family, Mr. Smith relinquished custody of Jill and she was placed (age 13) in the first of what ultimately became a series of over 18 residential placements over the next 3 years.

According to Mr. Smith, Jill's first 10 to 12 years of life were a real battle to survive; "[there was] lots of sexual abuse in her life. She 'came onto' and wanted to 'try out' every man who came along." She "blew through" four foster families and was on the street within 4 months. She reported that she liked her first foster parent home and felt that they were very helpful. She had been placed with a couple and was the only child in the home. According to Jill, "They gave me a lot of responsibility and helped me grow up. If I went out and was late, they grounded me. It was the first time anyone ever grounded me, and it worked. I never ran away from them. I did well there." Mr. Smith, however, reported, "She got along well there because she called all the shots. She controlled them so they got along together."

At that particular foster home, Jill reported that she received help with her homework from a neighbor and that she liked the school she was attending. She was especially taken with the fact that they had a "time out" room right in the school. She explained, "They had padded cells so you could remove the bad actors from class and not interfere with the others. It was neat to have a time out room right in school. If you were bad, they could throw you into the time out room so you didn't have to be yanked out of school." Very shortly after this placement, however, her foster family moved. She did not want to change schools, so she did not move with them.

The subsequent foster placements were in single parent households with other youth in the home. Jill reported that she did not stay long enough to find out whether they were good places or not. However, she was clear in her evaluation that foster homes should have two parents. She felt that two parents were needed in order to pay sufficient attention to the kids, to be able to do things with them. One parent was not enough. "A couple would be able to do more with the kids."



Shortly after her 13th birthday, Jill was picked up on the street, adjudicated in court for breaking windows "for fun," and sent to the youth detention center for a month, and then to an intensive treatment facility. According to Jill, it was "the last stop before jail." For the next 6 months she had incident reports about every 3 days and ran away about every 3 weeks. She was then sent to a psychiatric hospital for 30 days, followed by several further foster placements and one placement in a large 15-person group home, all of which she ran away from. She then spent several months at a youth shelter. Throughout this period of time, she was assaultive to her peers, attacked people with knives on several occasions, and made suicide gestures.

During this 9-month period, Jill also had several short readmissions to the detention center and psychiatric hospital until both refused to admit her for lack of "appropriate fit." The detention facilities found her to be mentally ill, not delinquent, while the psychiatric treatment facilities found her to be unmanageable and delinquent, not mentally ill. It was during this period that Jill had numerous psychiatric and psychological evaluations, all of which concurred that she was suicidal, highly aggressive, assaultive, extremely dangerous to others, and required long-term, locked, residential psychiatric care. The court readjudicated Jill "a child in need of supervision" (age 14:6) and placed her with her adoptive father until an appropriate placement could be made.

Jill stayed with Mr. Smith in his isolated rural home for most of the next 5 months, attending special classes at the local high school. During this time, Jill had one admission to a psychiatric hospital and one suspension from school. Jill described their relationship as follows, "Everything positive I did, Dad supported me. When I was negative, he let me do my own thing until it was over. Then he talked with me and gave me a lot of personal support. He ignored my tantrums, then came back and talked it out and joked with me." She said that her dad had a unique sense of humor. One time when she threw a bucket of water on her father he responded, "Now I don't need a bath. I've already had one." She reported that there was only one time that her father took all her privileges away based upon her behavior, "the time I was shooting at the neighbor's dogs with a bow and arrow. He warned me not to, and then took away the bow and arrows, and TV. It was effective."

That summer, she was sent on a trial placement to her biological mother whom she had not seen since age 2. This failed within a few weeks. The two fought constantly, often physically. Jill said afterwards that this was a helpful experience; "I got to meet my Mom. We didn't get along, so I got that off my mind and put it behind me." During that year, Jill's unmanageable and aggressive behavior continued and she was being considered for an out-of-state placement. All available programs and services had been tried and had failed; the only alternative to a long-term, out-of-state placement was AYI. At age 15, her case was accepted by the Alaska Youth Initiative.



#### Alaska Youth Initiative: Services and Outcomes

AYI established a Core Services Planning Team that cut across agencies to plan, coordinate, and implement services for Jill. The team was composed of Jill's social worker from family services, a high school educator from her community school, her adoptive father, the AYI coordinator, and, after they were hired, her professional parents.

The Core Services Team's individualized plan for Jill was to provide her with residential and educational stability while she learned behavioral self-control, personal responsibility, independent living skills, vocational skills, and completed high school. AYI recruited experienced, trained, professional parents to establish a small home in Jill's community to provide services and treatment for no more than three or four adolescents, including Jill. This couple had been trained in the Teaching Family Model, a behaviorally based, structured, behavior management approach to adolescent treatment. The group home provided milieu therapy by administering structure, control, responsibilities, and preestablished consequences through a point system. The youth living there were to learn peer cooperation and social skills through the structured home program while attending the nearby local school.

Finding and establishing an appropriate residence in the local community which could physically accommodate the professional parents, their biological children, and the treatment youth, however, took 8 months to accomplish. In the interim, Jill remained with her father, who had developed a serious health problem which continued to worsen. By the time Jill was placed, Mr. Smith was no longer able to provide care for her.

Jill resided in the teaching family group home for the next 2 years without running away. She spent the first 12 months as a group home member with two other adolescents. During the first 6 months, she assaulted another resident with a knife and, after assaulting him again, was sent to a psychiatric hospital for several days. During that first year, however, Jill formed a very strong bond with the teaching parents and her behavior improved dramatically. The few incidents that did occur, occurred when the teaching parents were on vacation. Throughout this time, Jill attended school on a regular basis, spending half of each day in a segregated class and half in a mainstream setting.

After the first year, the original teaching parents moved out of the home into administrative positions. During the next year, there were significant staffing changes among the live-in professional teaching parents. Jill became unhappy in the group home, largely due to personnel changes, and her behavior began to deteriorate. On one occasion, she engaged in extensive property damage to the group home, she got fired from a job for property damage, she tried several times to jump from a speeding car,



and she threw a car into reverse as it was traveling at high speed down the interstate in the company of a staff person whom she disliked intensely. In addition, she had one further admission to a psychiatric hospital for observation as a preventative measure when several of her school peers committed suicide.

Towards the end of the second year, Jill was moved into an independent living training program where she lived in an apartment which was physically attached to the group home. Jill was paying her own bills, shopping for herself, doing her own cooking, taking drivers education, and attending school regularly. Towards the end of the semester, however, she received a suspension from school and chose not to return, preferring to get a job and work on a GED through an adult basic education program.

Jill worked first at two fast food restaurants and then at a local supermarket, jobs which she obtained for herself based upon the training she had received from the job coach in special education at the local school. Jill held onto her supermarket job and worked on her GED for the next 4 months. At about that time, she requested termination from the AYI program. She asked her social worker, "What do you have to do to 'graduate'? I'm ready to move on." These requests, however, were largely ignored by her Core Services Team. Subsequently, when she had a misunderstanding with a shift staff person over her rights and privileges, she ran away to her boyfriend's apartment in another town, a youth she had met when she entered state care 5 years earlier and with whom she had a continuing relationship. At his request, she returned to the group home since she was under age, but a few days later she left again and went to her father's residence. He supported her in leaving the group home program. They met with the Core Services Team, maintaining that Jill had gained all she was going to gain by living there. The team agreed and Jill was released from state custody a few months short of her 18th birthday.

Following termination of state supervision, Jill moved to the neighboring town and took up residence with her boyfriend, whose child she was now carrying. Within a few weeks of her program termination, she had bought a car with her father's assistance, obtained full-time employment at a nearby fast food restaurant, obtained her drivers license, arranged for insurance, and completed the requirements for her GED; all of which were goals of her treatment plan.

AYI service outcomes for Jill were seen as being highly successful both by Jill and by her father. According to her father,

Jill has come a long way, gaining in maturity and self-control. Strict discipline is what she needed . . . being in control, having structure and consequences . . . She would have been a permanent resident of the juvenile detention center without the AYI option. She made significant progress, aging and mellowing, with AYI help. But the people who run it [the program] are the most important reason for her success.



Jill was interviewed 5 months after AYI termination. At the time, she was living in a three-room apartment in a medium-sized, two-story apartment building, about six blocks off a major thoroughfare in a fairly respectable-looking suburb. Jill was babysitting an 18-month old child and had a friend visiting her. She was very friendly, forthcoming, and displayed energy and positive affect in her interview. She appeared intelligent and insightful about herself and her behavior. She had a very clear memory of her 5-year social service history, and she was positive, although circumspect, about her experiences. She stated that she had been very rebellious and difficult in her youth and laid no blame for her behavior on anyone else. She had no anger or resentment towards anyone.

Jill characterized most of the services she received prior to AYI as being well intentioned: "They tried to deal with me, tried to talk with me, to help me deal with my problems," but they were largely ineffective due to her refusal to listen or to change. She did note that there was a "night-awake man" in one program with whom she had lengthy conversations and who indirectly helped her to problem solve interpersonal issues using the movies they watched on TV as material.

Jill was most enthusiastic about the AYI program:

They knew kids. They evaluated each kid as they came into the program. There was an individual program for each kid... I had extreme behavior problems, and wanted negative attention... They [the first teaching parents and some of the other staff] were very helpful... You can't let [your relationship with] a few people (disliked staff) interfere with the whole thing.

Due to complications of her pregnancy, she was forced to leave her restaurant job, but she obtained a desk job in a local business. She was extremely self-confident when describing that job and she was enthusiastic about her baby. She was actively spending time with a young mother and her infant in an upstairs apartment to learn more about taking care of babies and she was babysitting for the same purpose. She also had a considerable amount of reading material from her physician. She explained that both she and the baby's father were reading and preparing actively for parenting. She showed affection for the father in her manner of speaking about him, explaining that he had been her boyfriend since she was 13 when she was first in social services, and that they planned someday to get married.

What were the perceived accomplishments of AYI? After 2 years in state custody that included over 18 placements, 20 school suspensions, continual runaways, and aggressive, unmanageable behavior, Jill spent 3 years under the auspices of AYI in more stable residential and school environments. Nearly a year of this time was spent living with her father until he was too ill to continue. Two of these 3 years were spent in a group home placement. During this time, Jill had only a few school suspensions and two 3-day hospitalizations for observation. She made considerable gains in self-control and



in learning independent living skills, including work-related skills. Within a few short weeks of leaving the program to live with her boyfriend, she had completed most of the major objectives of her treatment plan.

## Evaluation: What Made It Work?

Consistent, structured supervision and enforcement of limits. Informants in this study were unanimous (including Jill) in identifying consistent, structured supervision and enforcement of limits as being a key element in program success. According to Jill, what was important was "people who grounded you." According to her father, "Strict discipline was what she needed and what she got from AYI."

Quality people providing the program. Another key element identified by Jill's father was the people running the AYI program. "The people who run it are most important." Several key persons in the group home program were identified as being especially caring and as having excellent professional skills. Jill formed very strong attachments to, and respect for, these individuals. These specialized teaching parents hung in there no matter what, embodying the unconditional care philosophy of AYI. According to Jill, "The teaching parents were the best. I had extreme behavior problems. I wanted attention for negative things. They would send me to my room. When I came down, they would talk to me and taught me that positive attention was okay; in fact, it was the best."

Developing trusting, respectful, mutual relationships. Developing trusting relationships with adults was important to success. Jill said that the continued support "no matter what" provided by her father through all the program changes and personal difficulties was very important to her. Her personal relationships with particular individuals providing AYI services also were important. Unconditional care was a means of developing these trusting and respectful relationships.

Individualization of services. The individualization of her treatment program provided by AYI was seen as critical by Jill. "They knew kids. They evaluated each kid as they came into the program, individually! They developed an individual program for each one."

Effective interdisciplinary teamwork. Several respondents in this study identified the interdisciplinary services team as being very effective, a key element. The team allowed participation of Jill's adoptive parent and also provided support for the teaching parents. The respondents felt that the coordination, planning, and support offered by the Core Services Team was unlike anything available in the regular foster care system.



Unconditional care and commitment. This was a critical characteristic of the AYI staff who worked with Jill. It was also a critical characteristic of Jill's adoptive father. During the time Jill was at the AYI group home, Mr. Smith maintained unconditional commitment to her, even when he was recovering from surgery. When she lost the privilege to visit him on weekends or holidays, he would come and visit with her at the group home. He was also very supportive of staff and would bring Jill back early from weekend visits as they requested if she had been behaving inappropriately. Mr. Smith was a constant, committed, actively participating member of Jill's AYI team, and a continuous support for her.

#### Barriers To More Effective Services

Inflexible programming. Issues of autonomy and flexibility were identified. Towards the end of the 2-year AYI period, some felt that the behavioral consequences used were not mature enough. Her father pointed out, "At first Jill needed strict discipline, but as kids get older, you need to let up, you need to lower the bars somewhat. AYI was a little slow doing that."

Multiple staffing and staff changes. According to Jill, "The point system was good as long as it was fairly implemented. Multiple staffing was a problem, it is like having two bosses, each expects something different. Staff changes and shift changes were confusing.

Inattention to youth and family input. There was a feeling at the end that the Core Services Team wasn't listening to Jill or her father well enough. Respondents strongly recommended that more attention be paid to parent and youth wishes, that there be a little more program flexibility, and that the core team include the youth more in planning meetings.

Group care. Too much emphasis in this case was placed on group care. In group care, the youth resides with a number of other disturbed youth who can facilitate or teach behavior escalation. The youth may also actively compete for adult attention with these other young people. Gains might have occurred earlier if Jill had been placed in an independent living situation sooner.

Insufficient skills and resources in the regular foster care system. The unconditional care of regular or specialized foster parents who can stay with the child and see him or her through unmanageable behavior is extremely important. This capability is rarely available in the regular foster care system. Jill also pointed out that, in her case, it would have been beneficial for the foster parents to have had kids of their own.



School and classroom segregation. Jill did not like being segregated in school with young people who had an assortment of labels and disabilities (in her case, developmental disabilities, a learning disability, and emotional disabilities all at once). She felt that individualization did not take place at school. She found her school placement stigmatizing, and she felt discriminated against. Also, having to change schools with placement changes was difficult.

Lack of a crisis backup. The need for a 24-to-72-hour crisis center to provide short-term backup in cases such as this was seen as critical. Youth with the labels of seriously emotionally disturbed often were seen as having a conduct disorder, not as being mentally ill, so psychiatric facilities do feel that it is not their appropriate role to provide crisis relief for these youth. A secure crisis management place would have been an important contributor to the positive outcome of this case and others like it.

#### **Conclusions**

After a 9-year history of serious abuse in her natural family, Jill began receiving services at age 12 with 4 months of family counseling. This was followed by 2 years of continuous failed efforts at residential placements, including more than 5 foster homes, 2 group homes, 2 psychiatric hospitals, a youth shelter, multiple placements at a secure youth detention center and a residential treatment center, and over 20 school suspensions. Jill was rebellious, aggressive, assaultive, unmanageable, oppositional, manipulative, hyperactive, and suicidal. She was diagnosed as conduct disorder and borderline personality, and by age 15 had multiple recommendations for a long-term, locked psychiatric residential placement. While efforts were made to access AYI as an alternative to a restrictive placement, Jill spent 5 months with her adoptive father, several weeks with her biological mother, and another 8 months back with her father.

AYI placement was implemented when Mr. Smith's health failed. Jill was 15. Jill remained in the AYI program without running away, attended public school regularly for nearly 2 years with a few brief suspensions and two brief 3-day stays at a psychiatric hospital for observation. Following a school suspension in her last year, Jill chose to work on her GED and obtained a job in the community. She stayed in AYI's teaching family residence continuously for 2 years. She made considerable gains in behavior control and learned skills for independent living, including work-related skills. As she became dissatisfied with staffing changes and house restrictions after asking for program termination, she ran away to her boyfriend and then to her father's home. A few months before her 18th birthday, she and her father had state supervision terminated.

Within a few short weeks of program termination, Jill had taken up residence with her boyfriend, finished her work for her GED, obtained a car, a drivers license, insurance,



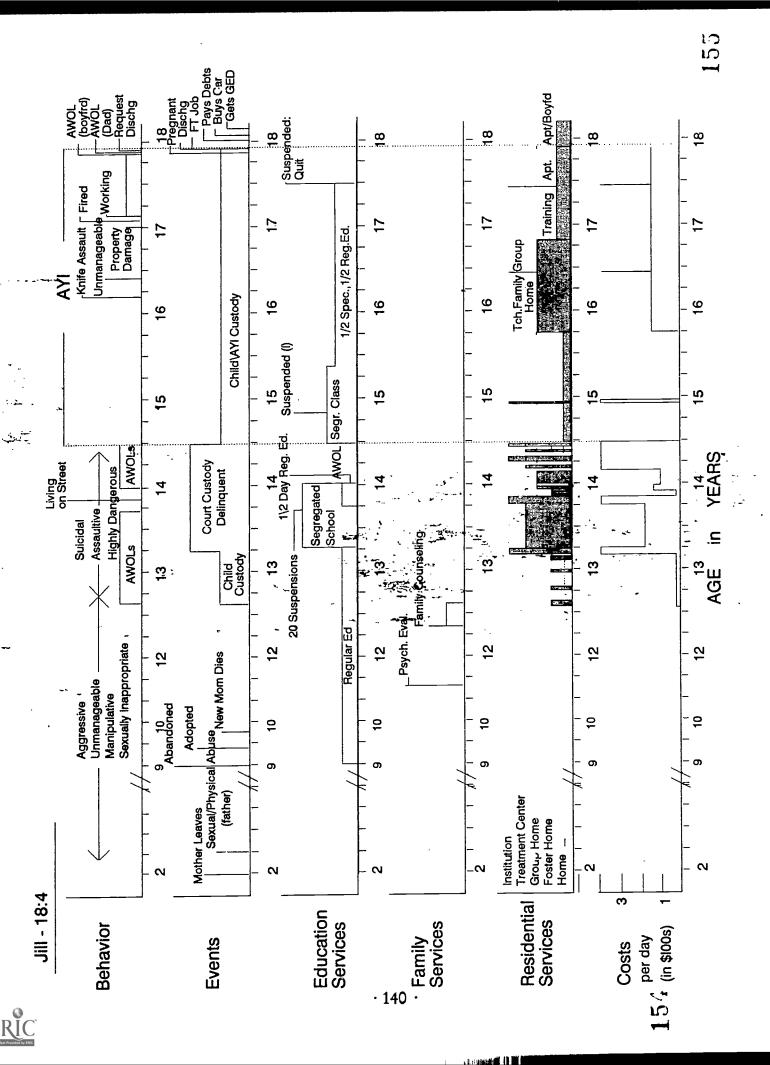
and a full-time job, all objectives of her treatment plan. She was also pregnant, actively involved in learning parenting skills with the baby's father, and anticipating the baby's birth and marriage. She evaluated her AYI involvement as extremely helpful, but also noted that she had outgrown the program and was ready "to move on."

During her time in AYI, Jill developed strong personal bonds with staff members and continued to remain in contact with them, occasionally dropping by to visit the teaching parents and staff. At the time this study was conducted, Jill didn't foresee any need for further services, but said confidently that if she needed help, she could get it through the several teaching parents who are her friends.

On the next page is a multiaxial timeline which represents Jill's major life events and behavioral history, the mental health, educational and residential services she has received, and the estimated costs of these services.

Sources of Information: Information for this case study was obtained from Jill's case records and from personal interviews with Jill, her adoptive father, Mr. Smith, the social service worker who worked with the family for 6 years, her AYI coordinator, two separate sets of teaching parents from the AYI group home, and the administrator of the psychiatric hospital.





# **SECTION II**

Project Development and Implementation of the Alaska Youth Initiative

Robert Sewell, Ph.D. John VanDenBerg, Ph.D.



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# Overview

Since well before the days of statehood, Alaska had developed the practice of sending many members of its most disabled, disturbed, and/or offending young populations to highly restrictive out-of-state placements (Oakley, 1988). These persons were typically sent to facilities throughout the "Lower 48" Western states. Of course, Alaska was by no means alone in this practice, nor has Alaska been the greatest user of out-of-state services (Moran, 1991). However, because Alaska has historically had very little in the way of an established social services infrastructure, the practice of sending highly troubled youth to out-of-state placements became a firm fixture in the Alaskan service system. From 1975 to 1985, the out-of-state census ranged between 50 and 200 youth at any one time.

During the mid-1980s, four major factors played a role in helping Alaska bring to a virtual close its practice of placing troubled youth in out-of-state institutions. The first important factor was that Alaska had the extreme good fortune of receiving one of the first 10 state grants from the National Institute of Mental Health's (NIMH) Child and Adolescent Service System Program (CASSP) (Schlenger, Etheridge, Hansen, & Fairbanks, 1990). This federal funding was provided over a period of 5 years to establish a child and adolescent program within the state mental health bureaucracy to help build a system of care for youth who suffer severe emotional disturbance. The CASSP mission, then as later, was to focus national attention and resources down to the state level so that each state could explicitly identify priority youth and reorient its system and resources to more fully and effectively serve this group. In Alaska, CASSP funds provided the flexibility necessary to begin the intensive effort to end out-of-state placements, for, although this effort was eventually supported with all of its own service dollars, marked organizational and systems costs initially had to be incurred at a time when Alaska was not disposed towards starting expensive, new programs (VanDenBerg, 1988).

A second factor was the increasingly vocal national movement to end the use of out-of-state care. This orientation was well articulated, for example, in the National Mental Health Association's white paper "Invisible Children" (1989). This deinstitutionalization message had an impact on some of Alaska's mental health leadership at that time.

A third factor was that the use of out-of-state facilities is an extremely expensive practice. From the mid-1950s until the fall of 1985, Alaska's economy demonstrated strong and sometimes unbridled growth largely fueled by natural resource development. State government budgets came to reflect this. Eventually, 85% of these budgets were derived from oil revenues. However, in the third quarter of 1985, the price of oil plummeted as a result of international oil politics, and with it went some of the state's ability to pay for out-of-state placements.

The final factor in this evolution was the establishment of a team of representatives from public child service agencies to explore alternative services. By 1985, senior staff in the Alaska state departments of education and of health and social services had come to realize that sending increasing numbers of emotionally disturbed youth to services outside of Alaska was causing problems. Costs were high, results were questionable, and both legal and ethical issues



were involved. The work of this team, made up of senior staff drawn from the Department of Education's Division of Special Education and the Department of Health and Social Services' Divisions of Family and Youth Services and of Mental Health and Developmental Disabilities, provided impetus to the movement away from using out-of-state placements.

By the second quarter of 1986, these four factors, among others, had conspired to bring to Alaska's CASSP effort the compelling mission of ending the use of out-of-state facilities for its youth who suffered severe emotional disturbance (VanDenBerg, 1991). That effort became known as the Alaska Youth Initiative (AYI).

At that time, there was little understanding of what would eventually be necessary to successfully return to Alaska some of the state's most dispossessed, difficult-to-serve children and adolescents. The model that was developed to accomplish this task was an individualized one, sometimes called "wraparound care" (VanDenBerg, 1989, March). Unlike the traditional model of categorical services where children are brought into pre-existing programs, individualized services involve an interdisciplinary team which sits down and asks the question, "What does this young person need so that he or she can get better?" The team looks at the youth not only from medical and psychological perspectives, but also with an eye to meeting the youth's needs for family and friends, for educational and vocational experience, and for safety. AYI adopted the key tenet of Kaleidoscope, an Illinois private, non-profit program which espouses "unconditional care" (Breed, 1985). Following this philosophy, youth cannot fail or be kicked out of a program. Instead, the individualized program must change to meet the changing needs and responses of the youth.

This section presents a brief summary of what eventually developed regarding the mission, goals, principal features, and functions of individualized care as it evolved in the Alaska Youth Initiative.

A GUIDE TO ACRONYMS

API	- Alaska Psychiatric Institute	IΒ	- Individualized Budget
AYI	- Alaska Youth Initiative	IDT	- Interdepartmental Team
CASSP	- Child and Adolescent Service	IEP	- Individualized Educational Plan
	System Program	ISC	- Individualized Services Coordinator
CMHC	- Children's Mental Health Clinics	ISMT	- Individualized Services Management Team
CST	- Core Services Team	ISP	- Individualized Service Plan
DAIC	- Daily Adjustment Indicator Checklist	LC	- Local Coordinator
DFYS	- Division of Family and Youth Services	NAMI	- National Alliance for the Mentally Ill
Ì	(within DHSS)	PCT	- Proactive Client Tracking
DHSS	- Department of Health and Social Services	SED	- Severely Emotionally Disturbed
D.MH/D	D - Division of Mental Health and	SESA	- Special Education Services of Alaska

SESA

SMI

- Special Education Services of Alaska

- State Individualized Services Coordinator

- Severely Mentally III



DHSS)

DOE

HRD

Developmental Disabilities (within

- Human Resources Development

- Department of Education

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# Mission

## The Goals of the Alaska Youth Initiative

The principal goals of AYI (at its inception) were to limit further institutional and outof-state placements; to transition back to Alaska the youth already placed out of state; and to provide special, individualized case planning, monitoring, program development, and funding for youth and their families.

In the initial years of the demonstration project, coordinated agency efforts implemented through AYI were for the most part successful in meeting these goals. Only two AYI youth were placed out of state during the first two years, and no youth returned to Alaska through AYI had to go back out again. Given this positive initial experience, the mission and purpose of AYI expanded and two more general purposes became articulated (Sewell, 1990d).

Goal 1: The first purpose of AYI was to produce marked improvement in the habilitative outcomes for specific, program-eligible youth. Thus, the first valued outcome for AYI was to produce demonstrable improvement in both the level of functioning and the quality of life for each AYI-eligible youth, while providing services in the least restrictive manner possible.

Goal 2: The second purpose was related to the nature of AYI as a demonstration project. This involved the discovery, adoption, and then dissemination of effective individualized care practices. Thus, the second valued outcome desired for AYI was to systematically identify and demonstrate effective practices of individualized service, and then to effectively transmit these practices to other service providers.

#### Population To Be Served

Eligibility. AYI's initial mission was to bring home to Alaska all those youth who had been placed in restrictive out-of-state facilities. Thus, all out-of-state youth were immediately eligible for AYI. As this initial cohort was returned, the politics, mission, and financing of AYI shifted towards preventing further out-of-state placements. In part due to this mission and history, AYI only considered eligible individual children and adolescents, and not families as such.

In-state youth could be found eligible for services up to age 18 and could remain in AYI's system through age 21. AYI used a standard referral packet (VanDenBerg,



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1989, November) which solicited information such as previous placement history, educational progress, adjudication history, previous psychiatric and psychological evaluations, custody status, and medications. Later, a behavioral checklist was added. Both custody and non-custody children and adolescents were eligible. Special education eligibility (Public Law 94-142) was also not required for potential AYI consideration. Strictly speaking, classification regarding particular DSM-III diagnostic category also was not required.

AYI developed a state-level, interagency steering committee which became known as the Interdepartmental Team (IDT). The IDT came to have several functions, one being to determine the eligibility of each referred, in-state youth in much the way that a hearing board or jury might (Russell & Hornby, 1989). The IDT really decided only one question: "Is there clear and convincing evidence that the array of component services within the youth's community of tie have been exhausted by the youth and his or her supporters such that the youth either stands at imminent risk for being sent to, or already is in, out-of-state placement?" This is a functional question and requires an answer related to the interaction between a given youth's severity of need and the existing resources within a given community of tie.

Following the virtually complete return to Alaska of all its out-of-state youth, AYI's eligibility question changed to focus on preventing out-of-state, and even out-of-region, placements (VanDenBerg, 1989). This second focus concentrated on youth who stood at high risk for being placed in, or who already were in, unduly restrictive in-state facilities, particularly ones which were far from the youth's home community. Clearly, this involved a very different politic and affected a much greater number of troubled youth.

The Priority Population. Many authors have worked to define which youth should constitute the priority population to receive child mental health services (Lourie & Isaacs, 1988; Stroul & Friedman, 1986). In 1984, CASSP adopted a set of five dimensions, or criteria, to guide states in identifying child and adolescent priority populations (Lourie & Katz-Leavy, 1987). These criteria were written broadly enough so as to allow states to further define the population in ways to meet each state's local needs. These criteria are:

- 1. Age Children and adolescents up to the age of 18 or 21, depending upon the state.
- 2. Disability Significant impairment of ability to perform in the family, in school, and in the community.
- 3. Multiagency Need Youth have a degree of disturbance such that services are required from at least two community service agencies.



- 4. Mental Illness Youth experience a mental illness or emotional disturbance which is classified according to the DSM-III schema, although the validity of that diagnostic system is in question.
- 5. Duration Disability has been of at least one year's duration (or conditions exist where professional judgment indicates that the disability is highly likely to be of at least a year's duration).

AYI essentially adopted these criteria. Its priority population thus became those children and adolescents who experienced severe disturbance with resulting marked functional disability; who experienced multiple needs which had to be addressed by two or more different types of services; and who experienced severe and multiple needs which were, or were likely to be, long enduring. Common professional usage (Stroul & Friedman, 1988; Torrey, Erdman, Wolfe, & Flynn 1990) identifies this group as "... youth with severe emotional disturbance," referred to as SED youth. Silver (1988) has proposed a set of diagnostic categories which, in sum, largely characterize the CASSP priority population. These diagnostic categories are: pervasive developmental disability (e.g., autism), mental retardation with other behavioral symptomatology, the affective disorders, schizophrenia, and conduct disorder. The vast majority of AYI youth had been previously identified with at least one of these categories.

Thus defined, AYI addressed the needs of only a small fraction of the Alaskan priority (SED) population. Although AYI accomplished the goal of virtually ending out-of-state placements and also produced a number of service system ripple effects, in scope it remained essentially a demonstration project. By the close of Year 5, a total of approximately 132 youth had been accepted into AYI's service (Sewell, 1991d).

# Principal Features of Individualized Care

During the 5-year demonstration project, 10 principal features emerged which appeared to contribute to effective individualized care (Sewell, 1990a and c). Each is briefly discussed below.

# Building and Maintaining Normative Lifestyles

The first dictate of the helping professions is to do no harm. Over the last 40 years, evidence has accrued in the literature that aggregate care and congregate living arrangements can do substantial harm to persons with disability and/or disturbance. It is now more clear than ever that placement of a youth in aggregate care does not necessarily equal appropriate treatment (Duchnowski & Friedman, 1990). Problems



with deviant modeling, lack of access to normative social networks, availability of contraband, victimization, undue stigma, and marked difficulty in program management, among several other problems, have all been amply documented (O'Brien, 1987). Nationally, the developmental disabilities service community has long articulated the value of mainstreaming persons with disability (Wolfensberger & Glenn, 1975). For AYI, this came to mean that individualized care should employ practices which are not unduly invasive and which do not create lifestyles grossly different from those of the general culture. This feature meant that individualized care and resulting lifestyles should be as culturally, ethnically, and age appropriate as could be arranged (Cross, Bazron, Dennis, & Isaacs, 1989). AYI's own experience soon made clear that the odds of success were enhanced if youth were served away from other persons with marked disturbance or disability and were dealt with as individuals within their own communities as much as possible.

A second aspect of building and maintaining normative lifestyles was deemphasizing a "cure" orientation for services and, instead, emphasizing the development of service strategies which support the youth's repertoire. The literature offers few examples of severe emotional disturbance being "cured." Supported living, supported learning, and supported employment service strategies (Rusch, 1989) all provide for ongoing maintenance of behavioral and quality-of-life gains in the least restrictive, most normative environments which can be arranged.

#### **Ensuring Client-Centered Services**

Traditionally, predesigned blocks, or components, of service are purchased from vendors by funding agencies with the use of relatively inflexible, or categorical, funds (Thompson, 1989). Such services tend to serve only given types of clientele, are available for only specified durations, and tend to be highly stylized. Component services are likely to have extremely limited flexibility regarding the types of services delivered, the types of staffing patterns available, locations of service delivery, ongoing modifications of service plans, and case-specific commitments of additional resources. Via what might be termed the "pull-out approach", youth often are brought to and are congregated at centralized facilities far from their home communities. Component services tend to exclude, or to serve poorly, youth with multiple, severe, and long-enduring needs. The traditional case management practice of brokering (fitting) youth into existing service slots (e.g., openings, beds, homes, or programs) is often only marginally useful. Component services typically change very little in the face of a youth's highly unique and/or evolving needs. The result is that the "fit" is often poor. As such services fail, these youth are said to fall through the cracks.



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With a mandate to serve out-of-state youth suffering extreme need, AYI came to recognize the value of using service plans which were multidisciplinary in origin and holistic in scope (Sewell, 1991c). Traditional psychiatric diagnostic categories tended to lend little to service planning, in part because of the highly idiosyncratic nature of a given youth's resources and challenges, even for those youth with identical diagnoses (Lourie, Behar, & Sewell, October, 1989). By degrees, individual service planning evolved. Highly personalized, youth-specific local service planning groups called Core Services Teams (CST) developed Individualized Service Plans (ISP). Critical to the effectiveness of needs-based service plans is the ability to assign substantive, client-specific resources carefully based on such plans (Friedman, 1988). As AYI increasingly moved toward client-centered services, the need to budgetarily treat each youth as an individual cost center became more pressing (VanDenBerg, 1990).

#### Providing Unconditional Care

Inclusionary Intake. Unconditional care meant that youth would not be rejected or found ineligible for AYI services because of the severity or multiplicity of their need (Dowrick, 1988). There developed a firm commitment within AYI to provide care to those youth with the most severe emotional disturbances. There were some youth who were accepted into AYI not necessarily because they were Alaska's most desperate and dispossessed citizens, but because of intense political pressures which were engendered on their behalf. The point here, however, is that youth were not found ineligible because their needs were too severe. For AYI, unconditional care came to mean that its individualized service had an inclusionary, rather than an exclusionary, intake policy (see Population section).

Youth Won't Be Dropped. In component services, extreme behaviors or severe needs often become grounds for a youth's dismissal from programs even though such challenging behaviors may be the very ones which defined the youth as qualified for that program in the first place. Thus, for AYI, unconditional care also came to mean that once a youth was found eligible for service, then that youth would not be dropped as a result of extreme needs which might become manifest (Burchard & Clarke, 1990). The mandate became "to do whatever it takes" to ensure that youth receive appropriate, effective services within the least restrictive environment possible. From this perspective, unconditional care allowed for occasional changes in placement, in placement type, and in community of service. Changes in placement sometimes clearly needed to occur, yet this is very different from being dropped from services as a consequence of bad behavior.

If extreme, challenging behaviors developed and produced service crises, then services were configured and reconfigured until there was resolution (VanDenBerg,



1988). The goal was to continue services for a youth until he or she had assumed a normative lifestyle and no longer needed AYI supports (AYI Interdepartmental Team, March 1991). In the early days of the program, little was known about how to actually create an unconditional care approach. As a result, a number of the early AYI youth fell through the cracks. Nonetheless, within AYI there developed an ethic that discharge from the AYI program would not be used, under any circumstance, as a threat against the youth in an effort to produce behavioral change. By degrees, it became increasingly difficult for anyone to conclude that a youth just didn't fit into existing services and thus needed to be dropped from AYI. Instead, when a lack of fit occurred, individualized services were reconfigured to match the youth's current needs. Those who provided a youth with individualized care would change the service plan, change service monitoring and information-flow channels, adjust the youth's casespecific budget, and buy or build new services relevant to the new circumstances. To sharpen the lines of accountability, one person, AYI's Local Coordinator, was assigned responsibility to ensure that services stuck with the youth, and that services and associated budgets were configured and reconfigured as the youth's needs changed. In practice, the ability to creatively develop robust and tailored therapeutic residential services was one of the most crucial elements in being able to keep the unconditional care commitment and, thus, to keep the youth in his or her community of tie.

## Planning for the Long Term

Support Strategies. Because AYI focused on youth with severe, multiple, and enduring needs, it was soon apparent that AYI youth were likely to remain in the program for extended periods of ti.ne. For example, during Year 1, no youth were discharged from AYI. In Year 2, only 11 were discharged (Sewell, 1991d). In regard to service planning, AYI increasingly recognized the chronic nature of the disabilities which these youth experienced. Service delivery to AYI's SED youth came to increasingly resemble those strategies employed by the developmental disabilities services community. AYI's efforts came to focus more on support strategies (such as helping youth to live, function, behave, and adjust better rather than focusing on discussion of "cure" strategies). Kazdin (1988) has provided a useful chronic disease model as a guide to improving support services for youth with severely maladpted behaviors.

Proactivity. Success for AYI was not based on expectations that episodes of disruption would be eliminated for a given youth. Rather, it was assumed that such episodes would occasionally continue to occur and that these always had the potential of constituting crises for the youth, the family, and even the service system. Service planning based on the crisis assumption required assurance that those adults who



surrounded a youth should expect crises, have preplanned interventions, and focus on gradual improvements. The objective was to help make episodes of disruption and crisis less intensive, shorter, less alarming, and less dangerous. AYI staff were encouraged not to view crises as reasons for giving up on the youth nor as causes for radical changes in placement. To deal with episodic crises, the youth's Core Services Team was encouraged to adopt a proactive approach, not to wait for crises to develop. By the end of AYI's Year 5, most of the Individualized Service Plans contained contingency plans for crises, complete with short-term, back-up alternatives such as brief hospitalization.

Generalization and Maintenance. For AYI, planning for the long term came to mean focusing on supported living (planning for 24-hour-a-day supports, if necessary) as opposed to relying on such traditional approaches as outpatient "50-minute sessions." Planning for chronicity meant focusing on "wrapping" residential and daily structure supports around the youth so as to build sustainable lifestyles with sustaining relationships. This type of planning meant focusing on ways to minimize the number of placement changes, thus keeping the youth within his or her community of tie and, by this, possibly preserving continuities in the youth's life. To the extent that continuities were deliberately maintained, generalization and maintenance of treatment gains could be maximized (Johnston, 1979; Stokes & Baer, 1977). Seldom did AYI simply deliver intensive services for brief periods and then stop. Instead, attempts were made to carefully plan gradual transitions from one service placement to another, if, indeed, such transitions were required. Unfortunately, on several occasions, detailed transition planning was not accomplished, diminishing a youth's substantial gains. Careful provision for behavioral generalization and maintenance proved critical in assuring that a level of improvement continued after a youth left a given intervention.

#### Working Toward Least Restrictive Alternatives

Normative Environments. It became an ethic of AYI to serve its youth in the least restrictive ways possible. In part, this meant that AYI was dedicated to delivering appropriate services to each eligible youth in as normative an environment as possible and in a manner as minimally intrusive as possible (see Mission section). In the early years of AYI, and particularly in the Southcentral region of Alaska, non-normative, highly restrictive placements were used with considerable frequency (such as in residential treatment facilities, long-term inpatient psychiatric wards, and juvenile justice centers). The habilitative results of this practice were routinely negative. In part as a result of this experience, by the end of Year 5, AYI's Interdepartmental Team (IDT) passed a policy which disallowed further use of aggregate care (in particular, residential care facilities and group homes) for all program youth (AYI Interdepartmental Team,



March 1991). The foregoing should not be interpreted to mean that AYI stood opposed to short-term inpatient psychiatric stabilization services. Many AYI youth required short-term inpatient stays which were requested, and endorsed, by program staff.

Return to Community. When it was necessary to place a youth in restrictive care, there was a concerted effort to transition the youth back to more normative settings as soon as demonstrable behavior change allowed. Whenever restrictive care was used, an effort was made to approximate normative, daily living as much as possible (such as placing youth in intensive, therapeutic foster care and family-style group homes). When circumstances allowed, decisions to place youth in highly restrictive settings occurred via consensus of the youth's Core Services Team. If the CST's decision was to place the youth in restrictive care, then planning for eventual community reintegration was often begun at that initial meeting when placement was decided. Once placed, the goal was always to rapidly transition the youth back to normative services delivered within the mainstream culture. The time, resources, and advocacy necessary to arrange for these youth-specific deinstitutionalizations were often extreme. As a consequence, by the end of Year 5, AYI's policy was to leave affected youth on the "sending" coordinator's caseload (with associated resources provided) rather than drop the coordinator's assignment while the youth remained in the facility.

Dimensions of Restriction. Restrictiveness can be thought of along several dimensions: physical, programmatic, chemical, geographic, and social (Sewell, 1991b). Each of the these five dimensions must be monitored constantly by the coordinator as well as by the whole CST. However, a particularly vexing and common type of restriction experienced by Alaskan SED youth has been geographic, wherein youth are removed from their community of tie and then sent to out-of-region facilities. This practice has often had several untoward effects, among the more serious being that a youth's links and relationships to his or her community of tie were disrupted or even destroyed. Undue placement in out-of-region facilities has often been predicated on the assumption that intensiveness of service equates with type of facility. That is, a youth could only receive "real" habilitation when placed in a hospital or treatment facility. In turn, this meant that the youth must, of necessity, be removed from his or her community and/or region. The placement histories of most AYI youth were littered with these types of service failures. Of course, the common rationale provided by service vendors was that distant, highly restrictive placement was in the youth's best interest, meaning that if the youth remained in his or her community, then he or she would constitute a danger to self and others. However, careful examination of the evidence usually revealed that the issue boiled down to staffing, supervision, and staffskill problems.

Empirical Question. Regardless of the dimension of restrictiveness, what constituted the least restrictive alternative for a given AYI youth was always an empirical question. That is, the answer was always related to what services could be created for the youth and how effective those services would be. The thinking regarding SED services was, and still is, that workers have little ability to predict what can, in fact, constitute the least restrictive alternative for a given youth. As a matter of course, Local Coordinators were faced with the question, "What do we need to find out?" The answer always related to what resources, creativity, risk management strategies, and staff skills could be intensively applied to the youth's service.

#### Achieving Provider Competencies

New Roles. With a mission to build and maintain normative lifestyles for SED youth, AYI faced the problem of providing staff-intensive supports in completely community-based settings. AYI workers needed to be very actively involved in the actual living and learning environments of each youth. Workers needed to directly teach the age- and culture-appropriate social, daily living, and job skills necessary for youth to successfully adjust in their communities. Closely associated with this was the routine need for workers to identify many naturally occurring resources within particular lifestyles of the youth. All this meant that staffing patterns, staff support strategies, and consultative and supervisory approaches needed to follow AYI youth out into their respective communities. This often required markedly new roles for AYI personnel. Considerable flexibility was also required in the development of highly personalized job descriptions, schedules, and the like. For example, varied contractual arrangements (as opposed to employeeships) were made, often with non-profit, private human service vendors as a way of coming up with the highly specific youth-worker "matches" in terms of mentors, aides, foster parents, companions, and supervisors. The unique qualities of some AYI youth, coupled with the rural and often remote nature of Alaskan lifestyles, encouraged the use of workers with varied types and levels of professional and experiential preparation.

Sources of Competence. Demonstration projects for services to severely needy clientele often have strong human resource development components (Christian & Hannah, 1983). However, during its initial 5 years, AYI never substantially achieved this. As a result, staff quality varied wildly across coordinatorships. There were several reasons for this deficit. A largely unavoidable one was that Alaska had, and still has, a marked absence of both service provision and training infrastructures. Nonetheless, considerable case-specific staff training was used with benefit (Oakley, 1988). In addition, some broader scale attempts at foster care training were tried. On balance, though, these efforts highlighted the truism that for training to have enduring impact,



it needs to occur in a supportive context (Stolz, 1981). That is, efforts to provide training, per se, in the relative absence of the other aspects of individualized care (such as flexible funding and accountability) produced little continued success.

For these and other reasons, staff recruitment and selection was relied on heavily to provide the workforce necessary to serve the AYI cohort. Because of the extreme expense these youth could potentially represent, sufficient resources were commonly made available to attract and retain quality personnel. Workers with developmental disabilities service backgrounds proved to be particularly adept at grasping the mission and executing the responsibilities of AYI.

# Obtaining Consensus Among Key Decision Makers

Interagency Collaboration. Early on, it became apparent that effective, holistic services for multiple-need youth required a high degree of interagency collaboration In particular, this collaboration needed to occur at both (Bruner, 1991). Interdepartmental Team (system) and Core Services Team (case-specific) levels. Successful Local Coordinators developed the skill of identifying, convening, and maintaining workable youth-specific groups of those key decision makers in each assigned youth's life. The performances of Core Services Teams were facilitated by the Local Coordinators. The major positive outcome was the production and maintenance of consensus between the youth's key decision makers regarding what characterized the youth's recent history (i.e., the preceding 90 days), what his/her specific needs were, what was in his/her best interest, and what the service plan would be for the ensuing 90 days. This consensus was critical because the multiple vendors typically involved in a youth's life often had sharply divergent views concerning these four issues. On a case-specific basis, this interagency, consensual process had to evolve but often required guidance and heart-felt advocacy by Core Services Team members.

## Funding Services With Flexible Budgets

Money Follows the Client. As a matter of business, each youth in out-of-state placement had specific, large amounts of money encumbered in his or her name for the purpose of meeting the holding facility's costs. Recognizing that intensive, community-based Alaskan alternatives would, at least initially, incur comparable expense, an effort was made to ensure that, whatever monies had been budgeted for the youth's out-of-state services, a similar amount of funds would be made available for services within his or her community of tie. It was in this sense that money was said to "follow the client." Once the youth was served within his or her community of tie and marked service change(s) became necessary, then the encumbered monies were allowed to be



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spent on newly identified service needs. This was the rudimentary beginning of having clients represented as individual cost centers at both the funder and vendor levels.

Identification and Brokering of Existing Services. Usually some relevant parts of the service continuum did exist within a catchment area (Jones, McDanal, & Parlour, 1985). An effort was made to use these component services as much as possible and meant that expenses assigned to AYI's flex-funds were minimized. Relevant line or supervisory workers within employed vendorships often became members of the youth's group of key decision makers (see CST section, below). In any case, even judicious use of the component care system often left large pieces of the youth's service plan without appropriate resources. By degrees, individualized budgets became more systematically available to fund those parts of each youth's plan which were not resourced through the component system.

Move Toward Individual Cost Centers. Numerous problems and points of contention developed during the effort to move away from categorical funding of service components and toward flexible funding of individualized care. Not only was this more rife with technical and regulatory problems, it also represented a marked shift in the potential benefits and risks for varied, key stakeholders. As might be anticipated, those who had the greatest vested interests (real or perceived) in categorical funding of component care became some of those who were most opposed to flexible funding of individualized care.

Parts of Each Individualized Budget. Over a 5-year period, there evolved a means to provide each accepted and assigned youth with an Individualized Budget (IB) (VanDenBerg & Sewell, 1991). Each Individualized Budget consisted of three parts: C1, C2, and C3. The part labeled C1 represented the youth's Local Coordinatorship cost which included such items as the coordinator's salary and other directly associated expenses (such as the coordinator's phone); C2 represented all other operating expenses (for the vendor) which were not youth specific and included such items as a small portion of the vendor's rent, insurance expenses, and accounting costs; and, C3 represented all those costs which were strictly identifiable from the youth's Individualized Service Plan. Expenses in C3 were derived from the ISP in a manner that provided a point-to-point correspondence between those action steps found on the ISP and those budgeted costs found on the IB. Together, C1 and C2 were termed the youth's Core Service Costs, while C3 was termed the youth's Flexible Service Costs.

Core Service Costs (C1 + C2). While a given youth's Flexible Service Costs (C3) could vary over a wide range depending upon an ISP's content, each youth's Core Service Costs (C1 + C2) were fixed and were ascertained by formula. For the statewide program, the value of C1 was determined by estimating the entire direct cost of one full-time case coordinator, and by assuming that a full coordinatorship case load would be six youth. In addition, C2 was determined by formula as being a proportion



of C1 costs. The economic reality of the C2 value was ascertained by a group of exemplary providers who established it as 1/3 the cost of C1. Thus, C1 = (Coordinatorship and Associated costs/6); C2 = C1/3); and Core Service Costs = (C1 + C2).

By the close of AYI's fifth year (1991), as a result of the program's experience and based on the Alaskan economy, C1 was set at \$9,000 and C2 was set at \$3,000 per annum; the Core Service expense was \$12,000 per youth per annum. Core Service Costs were prorated; if a youth entered the program 6 months into the fiscal year, the vendorship received 0.5 of the Core Service Cost's per annum value.

Flexible Service Costs (C3). A youth's Flexible Service Costs were derived from a direct costing out of the action steps listed on the youth's ISP. The layout of the C3 budget exactly mirrored that of the ISP. The purpose of this was to have a direct relation between fiscal and programmatic accountabilities. The coordinator had primary responsibility for ensuring that all C3 costs were related to the action steps listed in the youth's ISP in a direct, point-by-point manner.

As mentioned before, many ISP action steps could be resourced through existing categorical funding streams. For example, respite care might be provided through an existing, paid for respite service using a voucher system. In a second example, varied services might be included on a youth's Individualized Educational Plan (IEP) and paid for through the school district's special education department. Additionally, wherever possible, Medicaid, private insurance, and CHAMPUS (insurance for military dependents) were pursued as payers of first report. However, once all traditional brokering and case management steps were complete, there typically still remained several service needs which could be covered in no other way than through the use of highly discretionary, flexible funds. For this, there existed no programmatic cap regarding either the identity or the amount of an allowable expense, within broad limits. Fiscal oversight principally sought to establish that ISP action steps were reasonably developed (in content and format) and that resulting costs were derived in a direct and frugal manner. Laced throughout the flexible budgeting process was the recognition that early on services would often be intensive (and thus expensive) in a youth's intervention, and that those services, and associated expenses, for this youth were most likely to be known by adults closest to the youth and not by state-level bureaucrats.

Budget Request. A submission-of-budget request involved sending the detailed Individualized Budget, along with the associated ISP, to the State IDT for signature. Upon approval, the coordinator's agency would then submit a grant amendment to the State Division of Mental Health and Developmental Disabilities, as well as similar forms of request to the Division of Family and Youth Services and the Department of Education, depending upon the idiosyncrasies of a given youth.



#### Providing a Gatekeeper Function

Many Alaskan SED youth experienced removal from their community of tie because, in fact, an individual caseworker was exhausted, irritated, frustrated, unimaginative, concerned about his or her perceived personal liability, and/or lacked immediately available resources. Virtually all AYI youth had long and littered histories of summary removal from their homes, communities, regions, and even from the state, often due to a range of system issues. These reasons for invasive placement are quite different from those provided by an independent, interagency review committee which has carefully examined a range of evidence and has concluded that a youth is fundamentally unservable within his or her own community.

Early in the evolution of AYI, there emerged an apparent need for a clear separation between the mechanism which decided individual youth eligibilities (the jury) and the mechanism which arranged for and provided direct services to accepted youth. Without a clear separation, it was too easy for the service system to conclude that a given, highly troubled youth no longer warranted community services. The explanations to account for these exclusionary decisions were often ornate, and, of course, typically referenced the youth's best interests, but careful review of the details often revealed additional issues such as the convenience of staff, difficulties in reaching the family, and expense to the provider agency.

It was in this context that AYI eventually evolved the Interdepartmental Team structure which had a limited set of functions, one being to identify eligible youth. The state-level IDT, not local service agencies (alone or together), decided which youth constituted the priority population. This decision involved both the acceptance of youth into the program and the discharge of youth from the program. It was in this sense that the IDT was said to serve a gatekeeper function. This case review process provided a relatively independent authority which could make substantive decisions regarding a youth's service alternatives and welfare, apart from the immediate pressures and limitations of local service capacity. This process has been generally recommended by the National Mental Health Association (National Mental Health Association, 1989) and has also found some use in the developmental disabilities service community.

This process helped to determine as eligible only those youth who were the most difficult to serve, to focus on them for as long as they continued to evidence severe need, and to maintain this focus for only as long as priority services were needed. AYI's IDT gatekeeper function thus became one of the critical elements which helped to create unconditional care (see also, Unconditional Care section).



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## Developing Measurable Accountability

Ongoing, holistic assessment of progress and provision of remediating feedback are necessary for any organized effort (Gilbert, 1978). These factors become particularly acute when the effort is an interagency one that serves some of a state's most challenging youth, many whom are housed in rural or remote locations (Gossett, 1988; Sewell & Kutash, 1990). How well AYI performed this vital function largely depended on AYI's stage of development and on the particular coordinators involved. Ongoing, detailed monitoring was particularly important because changes frequently occurred regarding characteristics of both the youth involved and their respective service settings. The coordinators actually faced four inter-related problems. These challenges were: (a) to ensure that ISPs were being adequately carried out (quality assurance); (b) to maintain the youth-specific, interagency collaboration that was necessary to address a youth's multiple needs; (c) to avoid crisis-generated shifts in service plans (particularly ones unknown to the coordinator); and, (d) to remain routinely informed about a youth's changing needs so that case plans, services, and associated budgets could be adjusted in timely and flexible ways. Unless care was taken, these four case coordination problems could quickly grow unmanageable. These issues were more acute for those coordinators who had large caseloads which were markedly intense and/or far-flung. Such situations meant that coordinators had little time for routine monitoring and follow-up, activities which were critical to maintaining AYI youth within their own communities. When these situations deteriorated, casework became more episodic, more crisis-driven, and more difficult.

Monitoring was seen to involve both traditional quality assurance (e.g., is the intervention being executed as planned?) and an assessment of more ultimate outcomes such as the nature of the placement, the youth's overall level of adjustment, and the quality of life experienced by the youth. Responsibility for execution of the monitoring function remained more with the Local Coordinator than with either the State IDT or the other members of a youth's Core Services Team. Monitoring both a youth's behavioral adaptation and the performance of service vendors identified in the ISP presented a challenge.

# Operation of AYI: Referral to Acceptance

## Referral Sources

AYI remained a mechanism by which the public sector might identify those children and adolescents most in need of intensive, holistic services. Four types of referral sources were possible (Alaska Department of Health and Social Services, 1987). Eligible referring agencies included any community mental health center (n = 28); the Alaska Psychiatric Institute (API), a public agency; any local school district's Department of Special Education (n = 55) in combination with a statewide consult agency (SESA); or any local DFYS office (either child protection or juvenile justice). With time, the IDE developed an informal bias toward those referrals which originated from local interagency efforts. Various, plausible referral sources were disallowed, such as parents, private psychiatric hospitals, and emergency shelters. Importantly, the local AYI coordinators were also disallowed from being formal referral sources. The coordinators could give general advice and guidance regarding potential services, but were strongly encouraged not to actively participate in the referral process. This disallowance evolved only slowly in AYI and was the result of repeatedly observing potential conflicts of interest.

#### Submitted Materials

A wide variety of materials was requested and accepted by the IDT in the AYI referral process (Alaska Department of Health and Social Services, 1987). In general, information was presented on whether or not the range of community resources had been exhausted such that the youth in question either already was in, or was at imminent risk of being placed in, an unduly restrictive out-of-region placement (see Eligibility section). Because AYI youth represented a broad spectrum of service needs, the IDT avoided highly circumspect requirements as to which documents would constitute sufficient evidence of resource exhaustion. In general, however, requested materials included psychological and psychiatric reports, child protection and juvenile justice records, vendor case notes and progress reports, restrictive-care placement histories, school records, and similar documents. While important, these submitted records were not the sole source of input which shaped the IDT's decision since a telephone case conference hearing also figured prominently in the process.



#### Interdepartmental Team

Membership. The Interdepartmental Team was comprised of one mid-level manager from each of the three principal state agencies involved in AYI, thus yielding a total of three members at any one time. These agencies include the Department of Education's (DOE) Division of Special Education, the Department of Human and Social Services' (DHSS) Division of Family and Youth Services (DFYS), and DHSS's Division of Mental Health and Developmental Disabilities (D.MH/DD). Within DFYS, for a variety of contextual reasons, it was the concerns of child welfare which were principally voiced rather than those of juvenile justice. Similarly, D.MH/DD put a decided emphasis on menta' health concerns, with developmental disabilities being much less well represented. As regards program leadership, the voices of public health, Medicaid, domestic violence, vocational rehabilitation, formal advocacy, parent organizations, and the private sector were never appreciably represented.

Leadership. For several reasons, D.MH/DD demonstrated significant leadership in both the initial formation of AYI and later in its growth and maintenance. As mentioned, one important reason was that Alaska was one of the first 10 CASSP states and, as such, received substantive funds for 5 years to engender within the state's mental health bureaucracy a focus on services to youth with severe emotional disturbance.

#### Functions. The IDT performed four principal functions:

- 1. Gatekeeper The IDT served a "gatekeeper" function, first by providing for the identification and acceptance of the highest priority youth and, second, by identifying those currently served youth who appeared to have received benefit from AYI to the point that the component system could serve alone. Thus, the IDT functioned as a "jury" for the purposes of admission and discharge.
- 2. Advisor The IDT served to advise Local Coordinators, community-level interagency teams, and other parts of the state bureaucracy with regard to service and administrative issues. The IDT provided ongoing advice concerning what constituted appropriate service plans and reasonable budgets.
- 3. Funder As discussed elsewhere, each youth was provided with an Individualized Budget predicated on an Individualized Service Plan (see Flexible Funding, and Funding the Plan sections). To a considerable degree and by a prescribed mechanism, the authority to spend resided with individual IDT members. As ISP and associated budgets were approved, the IDT concluded and signed client-specific joint funding



- agreements. Numerous considerations factored into decisions regarding relative contributions from the three funding sources, but, inevitably, these proportions were established through consensus.
- 4. Program Manager In several respects, the IDT also provided program management, helping to determine policies, procedures, expectations, and lines of authority and communication.

Identification and Remediation of Service-System Gaps. While each IDT member performed the above-described functions for AYI, the majority of each member's job was focused on his or her own system's component services. Youth who experience severe, multiple, and long-enduring needs have a way of forcing responsible workers to see the variety of deficiencies, or gaps, within their catchment's service system. Often, such multiple-need youth do not neatly fit into preciesigned intervention packages. Because of their multiplicity of needs, such youth may not be seen as the principal responsibility of any one vendor type. This can easily degenerate to the point where the youth is nobody's responsibility. Being responsible for holistic oversight of services to these youth, IDT members (as well as AYI Local Coordinators) were in a good position to comment on, and help remediate, service gaps which had been brought into sharp relief via the AYI process. It was perhaps in this sense that IDT members came to feel that they were "changing the system, one kid at a time."

#### State Individualized Services Coordinator

In addition to the State IDT, there came to exist the position of State Individualized Services Coordinator (State ISC). During the first 4 years of AYI, there was no distinct State ISC position and the role was being filled by the State's D.MH/DD Child and Adolescent Mental Health Coordinator, who also sat as a voting member on the IDT. This double-duty situation was the result of several factors, including the evolution of the project, personalities, and barriers to establishing new DHSS positions. However, by the beginning of Year 5, the AYI project was able to expand positions at the state level to include both a State ISC and a project assistant. The State ISC position provided oversight and guidance for the entire AYI project. The position had as its principal consumers the set of Local Coordinators, and it had as its oversight the state's Interdepartmental Team. While the State ISC was a source of input, that position was explicitly not a voting member of the IDT, in part for the sake of maintaining a clear separation between decisions to serve and mechanisms of service. By the beginning of Year 5, creating this full-time position was long overdue, as it was apparent that a state individualized services effort had to be extremely staff intensive. This fact was compounded by the often highly politicized nature of the served youth and by the frequently complex funding streams involved in resourcing many of the AYI youth's



Individualized Budget. The complexities of the financing alone eventually were grounds for the establishment of a full-time project assistant position to manage the individual cost-center funding arrangements.

# Administration-IDT Relationship

By the end of Year 5, the directors of the three participating state divisions were identified as the Individualized Services Management Team (ISMT). Although the ISMT voiced strong support for AYI and allowed for joint funding contributions, in fact, program management continued to reside with the mid-level IDT. This IDT existed just below the level of political appointment. This structure was useful in providing relative continuity through changes of state administration, but was not without its difficulties. Each of the three IDT members was responsive to the head of his or her respective division. During the first 5 years, each division's position of director turned over three times, as did those in the position of commissioners of DHSS and DOE. Maintaining top-down stability, commitment, and vision often proved to be a process-intensive, time-consuming, and risk-incurring task.

Because of the tremendous amount of bureaucratic trouble, risk, and expense which AYI necessarily either highlighted or engendered, there were numerous times during the first few years when AYI came to the verge of going under. That this did not happen is probably the result of several factors. Briefly, these were: the existence of a relatively clear interagency responsibility; a compelling social problem that AYI was specifically directed to address; significant advocacy forces external to the bureaucracy (e.g., National Alliance for the Mentally III); and, though replete with difficulties, an effort that yielded successes and cost-effectiveness significantly greater than those engendered by business-as-usual programs.

The degree to which AYI might actually be considered an interagency effort varied considerably with the epoch of leadership. In the end, the interagency collaboration which developed was more the result of the sociological and organizational context within which AYI existed than it was the result of any formalized, written agreement. The vast majority of persons involved with AYI neither saw nor were aware of any written, omnibus interdepartmental agreements.

# State-Local Relations

Use of Private Non-profits. At first, there was some thought that client-level service c ordination would be done via state employees, probably from D.MH/DD. In fact, the first coordinator was a D.MH/DD mental health clinician. However, three



enduring problems became evident. First, for a Local Individualized Services Coordinator (Local ISC) to be effective, that worker had to be able to quickly spend substantive monies on a case-specific basis. Due to the slow and inflexible nature of the state bureaucracy, this ability was almost completely precluded. Second, a Local ISC had to be able to readily assign and dispatch staff on a case-specific basis. This function, too, was almost completely precluded by traditional state personnel procedures. Of necessity, case-specific spending and staff assignment were soon accomplished via the action of associated private non-profits. Third, as part of a general effort to maintain a ceiling on state hiring, the state administration and legislature remained very reluctant to expand the number of line caseworkers. Eventually, all Local ISCs were employees of public or private non-profits, with none being state workers.

Local Service Coordination. Initially, there was some interest in establishing regional AYI offices. In theory, regional offices responsive to a regional leadership would plan for, fund, and monitor individualized services within that region. Several factors eventually mitigated against the use of a regional structure. First, there was no point-to-point correspondence regarding the catchment areas of the three participating agencies. Second, the realization developed that the best service plans were crafted by those closest to the child in question. Third, a concern developed regarding the viable translation of the AYI model from a top-down, state-controlled approach to non-state, community-level leadership. In brief, concern centered on two issues: (a) assurance that spending would remain strictly individualized, that is, youth-specific; and (b) assurance that acceptance and discharge practices would keep the service available only for the priority population on a case-specific basis, and only for as long as a given youth's needs remained intensive. There was concern that regional structures might be strongly motivated to spend flexible funds on components of care rather than to resource individual client budgets, and/or they might begin focusing on youth of lesser need (non-priority) because they were essentially easier to serve, representing less risk and less cost. Closely related to the "model-fidelity" issue was a fourth concern, namely a realization that AYI, as a model services effort, was still evolving and, in many respects, largely remained to be elaborated and codified. If AYI were to be decentralized prematurely, the effort might easily be splintered and diluted by at least three separate leaderships.

Given the above, AYI retained significant state leadership in the four above-mentioned areas: gatekeeping, funding, advising, and program management. As AYI grew, however, it became less and less tenable for actual service coordination to occur at the state level. This was abundantly clear by the end of Year 1 (n = 20 youth). Slowly, the initial regional AYI efforts began to erode and the role of the Local Coordinator emerged. Increasingly, the relation between the Local Coordinators and the state IDT became a partnership.



#### The Eligibility Hearing

Qualified agencies could submit referral materials to the IDT on an ad hoc basis as youths were identified. An IDT eligibility hearing was then typically scheduled to take place within 2 weeks. IDT members received copies of the referral packet to preview. A project assistant would schedule the various persons relevant to the youth's current circumstance for participation at the hearing (typically, via teleconference). The number of witnesses usually ranged from 4 to 20, and the hearing lasted about 45 minutes. Hearings were convened as requested, independent of whether AYI had funds currently available to resource an anticipated plan. In this sense, AYI retained a rolling admission policy.

#### The IDT Decision

Acceptance into the AYI program required unanimous approval of the IDT. Only three choices were available to the IDT: (a) acceptance, (b) rejection, or (c) request for information. For expedience, IDT decisions usually were made immediately following the hearing, at which time a signed IDT Decision Form was faxed to the identified referral source. Although data on this issue remain lacking, approximately only 1 in 3 in-state youth referred to the program were accepted into AYI. Only in a very few referrals was there a request for additional information. By the end of Year 5, approximately 132 youth had been accepted. Within broad limits, youth were judged as eligible or not eligible for AYI independent of current availability of funds.

If a youth was rejected for admission, it was because the IDT did not unanimously conclude that there was clear and convincing evidence that the array of relevant component services had been exhausted for that youth within his or her community of tie. The vast majority of non-eligible youth were, nonetheless, youth who demonstrated extreme, long-enduring, and multiple needs. Regarding youth rejected from AYI, the IDT asserted that the local service community could do a good deal more to effectively serve the given youth. The basis for this decision derived from the submitted materials, from testimony at the hearing, and from the direct experiences each IDT member had accrued concerning the community-of-service in question. If a youth was rejected, the IDT typically provided suggestions regarding how local workers might improve services without AYI assistance.



# Operation of AYI: Acceptance to Service

#### Acceptance

As discussed before, when determining AYI eligibility, the IDT decided essentially only the question concerning local exhaustion of the component service system (see Eligibility and IDT Decision section). IDT deliberation continued in private immediately following the scheduled eligibility teleconference. If the decision was affirmative, then the youth was considered "identified" or "accepted." An IDT Decision Form was signed, and the referring source, as well as the affected coordinator, were immediately informed. In later years, an extensive Summary of the Eligibility Hearing form was also employed, copies of which were sent to affected parties.

#### Waiting List

Acceptance into AYI did not equal assignment of the youth to a Local Coordinator with a concomitant start of individualized care. For coordinator assignment to occur, substantive funding for the potential service plan needed to be found. Particularly towards the end of every fiscal year, the wait between acceptance and assignment was often lengthy. Nonetheless, at no time was there a moratorium on IDT Eligibility Hearings, regardless of the resources currently available to the IDT. Several system benefits derived from not stopping the identification process. Principal among these was the fact that the extant social need was always much greater than the service capacity of AYI, yet the overriding social mission of AYI was to prevent the further use of out-of-state placements both by providing a gatekeeper mechanism and ilso by providing strong service alternatives. Secondly, maintaining a rolling admissions policy helped to make sure that AYI retained visibility in the service community regardless of the program's current resource status. Thirdly, in virtually every fiscal year, the need for AYI services outstripped the available resources to the point that the service system was eventually forced to provide additional funds before the end of the fiscal year. For concerned child advocates, the rolling admissions policy was a welcome addition to Alaska's case-specific advocacy efforts. However, the rolling admissions policy inevitably produced a problematic waiting list every fiscal year.



## Availability of Funds

Following acceptance, all youth began their sojourn in AYI with the status of Active: No-Funding. Accordingly, no AYI monies nor significant personnel resources (including those of the Local Coordinator) could be spent on the youth until the IDT formally changed the youth's status to Active: Funded. For this change in status to occur, the IDT had to identify substantive funding to resource the youth's anticipated budget. This arrangement was used for several reasons, an important one being to ensure that vendorships would not be forced into taking additional extreme-needs youth without receipt of substantive additional funds. A second reason was that this arrangement left the IDT carefully in possession of the final, empowered prerogative and duty to determine the adequacy of both submitted plans and associated budgets. Various other funding schemes which were considered at one time would have considerably diluted the relationship between client-centered service planning and availability of funds.

General, high-side estimates were obtained about the amount of funds required to resource a given youth's anticipated service plan. Through IDT action, the conjoint bureaucracy would then find and encumber needed funds. In many ways, this was an informal process, some would say a covert, or even mysterious, one. This was unfortunate since the relative lack of fiscal procedures, particularly during AYI's early years, continually produced unnecessary divisiveness and frequent inefficiency.

In any case, early in each fiscal year, funds were readily available through separate budgets allocated by the legislature to D.MH/DD, DFYS, and DOE. Yet, later in the year, after all discretionary funds had been encumbered, the resourcing of newly accepted youths' ISPs became much more problematic. Nonetheless, the conjoint bureaucracy would episodically, and on a youth-specific basis, find the resources necessary to fund additional youth. At that juncture, all IDT members would sign a youth-specific IDT Budget Decision Document and the youth's status would be changed to Active: Funded. Once the IDT Budget Decision Document was signed, the IDT was in a position to assign the youth to a Local Coordinator.

#### Assignment

The IDT Budget Decision Document, including a Coordinatorship Assignment Record, was then faxed to the relevant Local Coordinator. As of the date on which the Local Coordinator signed the Assignment Record, the youth was removed from the waiting list and entered actual AYI services. The Local ISC and his or her agency's director had to both sign the Assignment Record for completion of the assignment process. This signature pledged the local agency to three things: (a) that it would fulfill the AYI



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Coordinatorship Functions; (b) that it would serve as fiscal agent for resourcing the youth's ISP; and (c) that it would provide, create, or broker services for the accepted youth in keeping with a set of 10 principal features, described earlier in this section, which have come to characterize effective individualized care.

Upon formal assignment, the Coordinatorship was then allocated Core Service (C1 + C2) Funds on a pro-rated basis (see section regarding Individualized Budgets). However, as has been mentioned, Flexible Service (C3) Funds were not made available until the coordinator submitted a detailed ISP and a closely associated Individualized Budget. For this, the Local Coordinator had to identify and convene a youth-specific Core Services Team (see Flexible Funding and Submission of Budget sections).

#### Local Coordinator

General Characteristics. By the end of Year 5, there were 10 Local Coordinators, scattered through the following localities: Ketchikan, Sitka, Juneau, Anchorage (2), Wasilla, Kenai (2), Kodiak, and Fairbanks. Two were housed in public, non-profit organizations, and eight in private non-profits. Three operated out of developmental disabilities agencies, and the remainder worked out of mental health services (all but one being CMHCs). It is of note that those workers from service backgrounds in developmental disabilities performed in an outstanding manner, yet all except 1 of the 10 coordinators were not qualified mental health professionals. In general, the exemplary performance of the developmental disabilities workers might perhaps be traced to that field's enduring reliance on focusing directly on skills development (of both service recipients and providers) and on creative resource configurations and reallocations. This is as opposed to putting mental health's traditional, overwhelming focus upon the verbal behavior of its clientele.

Local, Not Regional. As mentioned before, there was initial thought that service coordination would best reside at the regional level, potentially with state employees. In the end, this was judged to be neither desirable nor viable. For about the first 4 years, three regional offices evolved, one in each of the following areas: Northern (Fairbanks), Southcentral (Anchorage), and Southeastern (Juneau). As the caseloads grew, it became less tenable to serve such severely needy youth stretched out over such vast catchment areas. Additionally, inherent in this regional structure was the problem of an external authority imposing upon localities the requirement of providing care to some of the system's most difficult-to-serve youngsters. Due to these and other pressures, the regional concept eventually was replaced by the Local Coordinator, also known as the AYI Coordinator or the Individualized Services Coordinator.



Functions of the Coordinator. Eventually, AYI identified a set of principal functions which appeared to characterize the performance of effective Local Coordinators (Sewell, 1990b). These are briefly listed below, independent of priority:

- 1. Fostering interagency collaboration, particularly regarding operation of the Core Services Team.
- 2. Preparing Individualized Service Plans.
- 3. Monitoring behavior and progress with respect to Individualized Service Plans.
- 4. Identifying, brokering, and case managing of existing, generic services.
- 5. Identifying and remediating service-system gaps.
- 6. Designing and creating individualized care when needed services do not exist for a particular youth.
- 7. Preparing Individualized Budgets resourced by flexible funds.
- 8. Providing direct services when these cannot be brokered from elsewhere or created.
- 9. Advocating for the rights and needs of individual youth.
- 10. Disseminating information.

#### Core Services Teams

The Consensus Meeting. Youth referred to AYI typically displayed severely maladjusted behaviors. Such youth demonstrated multiple problems and, typically, had been served by multiple vendors. Thus, by the time a youth entered AYI, several key decision makers were commonly involved in his or her life, and such persons often neither knew nor trusted one another. For such youth to be successful in a community, a high degree of coordination and collaboration was required between the adults involved. A concrete, yet evolving, written case plan was thus required based on group consensus and centered on guiding varied service deliveries, often over many months or years. The periodic meeting in which the Individualized Service Plan was produced and reviewed might well have been simply termed the Consensus Meeting. In AYI, this became known as the Core Services Team (CST) meeting. Without routine, youth-specific, interagency group collaboration, these multiple-need youth commonly failed, ending up in highly restrictive care and/or in out-of-region



placements, with no small number simply dropped from services altogether (VanDenBerg, Sewell, & Kubley, 1991).

Coordinator's Role. One role of the Local Coordinator was to facilitate the CST meeting. The coordinator was encouraged to build and maintain a team approach characterized by cooperation, initiative, and mutual respect. Several steps were involved in establishing and facilitating CSTs (Sewell, 1991a). Following acceptance and assignment, the Local Coordinator identified between 5 and 12 responsible adults who knew the youth well. For a given, highly politicized youth, a few instances occurred of CSTs initially numbering between 18 and 24 members. However, as case specific progress emerged, membership commonly declined, and meetings became shorter and less acrimonious. CST meetings were scheduled so as to encourage maximum participation. After the initial CST planning meeting, the group was asked to reconvene at least every 90 days to review and update the youth's service plan. Meetings lasted about 1.5 hours per youth.

Membership. The goal was to have the CST composed of a multidisciplinary group of both lay and professional persons who had been involved in the youth's life for some time. In virtually all cases, the youth's legal custodian(s), usually the parent(s), were present as well as a mix of persons who represented other varied parts of the youth's life. Typical additional participants included, but were not limited to, a social worker, guardian ad litem, probation officer, public defender, minister, psychiatrist, psychologist, special education teacher, school administrator, professional advocate, and relatives and/or significant others. Generally, it was important to have at least one central person from each of the following parts of the youth's life: (a) living environment, (b) daily structure (usually school or vocational setting), and (c) treatment or habilitation service. However, particularly during early planning phases, it was wise for the coordinator to over-include when forming the CST. Initial over-inclusion often promoted that kind of creative problem solving which resulted from having varied points of view present.

CST Meeting - Goal. One of the ultimate purposes of AYI was to produce demonstrable improvement in both the level of functioning and the quality of life for each AYI-eligible youth, while providing services in the least restrictive, most normalized manner possible. To fulfill this purpose, the CST attempted to design services yielding a lifestyle which was both age- and culture-appropriate and which was physically and socially integrated into mainstream society as much as possible. There was an effort to avoid aggregate housing and congregate treatments. The coordinator guided CSTs toward use of least restrictive service alternatives as regards both living arrangements and daily structures (see Least Restrictive Alternative section). The main CST goal was to agree on a holistic service plan which was highly individualized and tailored to the youth's exact needs. By the end of AYI Year 5, the plans which



emerged typically were detailed and readily formed the basis for case-specific, individualized budgets (see Flexible Funding section).

CST Meeting - Format. The following format proved useful for the CST meeting. Discussion typically began with a review of the youth's recent history (the preceding three months). After this discussion, the youth's current range of needs was examined. Finally, need statements were translated into critical action steps involving particular services. Whenever possible, closure on specific action steps was sought. Discussion usually began with the parent(s), or other person(s) who actually lived with the youth. Each participant was encouraged to give substantive input regarding history, needs, and proposed action steps. Because AYI youth often posed significant risk, carefully drafted contingency plans frequently were agreed upon. These plans specified how crises would be handled and what roles, if any, the varied team members would play.

Problems Encountered. Throughout the initial 5 years, varied barriers emerged in CST meetings regarding both content and process. What follows is a brief description of some of these barriers.

- 1. "Generic-Think" This referred to the unfortunate but common practice of making quick leaps to summary remarks about the need for specific services or vendors. This practice was often based on the traditional search for and brokering of available slots to plug kids into. This is exactly the opposite of what AYI was about. Problems emerged when members first discussed those services which they had available, and only later considered carefully discussing exactly what the youth specifically needed. Coordinators varied wildly in their abilities to remain needsfocused (vs. available services-focused). It is perhaps common that those workers who have spent their careers hunting for available service slots have subsequent trouble reorienting to a primary focus of doing whatever it takes to provide personalized services which meet a youth's previously identified range of needs.
- 2. Routine Answers to Complex Issues Closely related to generic-think was the practice of glossing over the sometimes minute details associated with a particular youth's situation. As time passed, it became increasingly evident that for the CST process to be successful, discussions needed to remain as flexible, creative, and client-centered as much as possible.
- 3. Adversarial Relationships Resistance was relatively common regarding new things, particularly when the discussants had worked for years with old answers which had repeatedly ended in failure. Occasional CS'I members remained oppositional to new concepts, regardless of a plan's



- actual content. In such circumstances, successful coordinators remained persistent, diplomatic, and continued to maintain an attitude of "...doing whatever it takes."
- 4. Philosophical Positions On occasion, some CST members would engage in broad philosophical discussions. However, lengthy discussion of philosophical differences rarely contributed to quality service plans. To avoid this problem, successful coordinators tried to work toward getting commitments regarding a plan for the next 90 days. This often helped to keep discussions kid-oriented.
- 5. Preemptive Remarks Successful CSTs remained cautious about varied kinds of preemptive remarks such as: "That will cost too much," or, "We've already tried that," or, "That's just not available." Quite often, what was being discussed had not been specifically tried, and cost less than people initially thought. Preemptive remarks usually just stymied the very creativity, leadership, and ownership which was most needed. In fact, it often appeared that this kind of talk was offered for the actual purpose of ending the very problem-solving effort which was the CST's mission.
- 6. Blaming Occasionally, and in part because AYI youth often represented marked complexity, expense, inconvenience, and risk, the CST process would be affected by blaming, recrimination, and divisiveness. However, there were so many long-past reasons as to why a given youth had met repeated failure that there was no useful way to go back and reconstruct who was to blame. Successful coordinators helped the CST retain as one of its most important goals a group consensus as to where the situation was going from here.
- 7. Turf Issues Within the CST process, there were frequent references to "whose kid he or she was" (turf), funding streams, and referral sources in an effort to ascribe responsibility or prerogative. In reality, all AYI youth experienced multiple needs and had been chronically involved with multiple service vendors. In an important sense, the youth's problems were no single person's responsibility; they were the CST's responsibility.

The CST consensus process was valuable for several reasons. One important reason was that it strongly reduced liabilities by several means. For example, if a potential liability occurred, a written plan generated by a multidisciplinary group which had produced public, documented consensus would be helpful in meeting the "reasonable man" test in the courts and newspapers. This meant that other workers,



when put into a similar circumstance, would have decided the same thing. The CST group process helped to meet this criterion, de facto. In addition, the CST process helped to provide considerable added oversight, support, and problem solving regarding the management of extremely challenging, difficult-to-serve youth. This type of routine interagency collaboration certainly helped to meet, and even to exceed, current standards of practice. Thus, no matter who the legal custodian was, this group process and the resulting written document helped to reduce everyone's liability.

It was useful and fair to include the youth as a member of the CST whenever possible. This was particularly true for transition-age youth. However, a two-tiered meeting format eventually emerged which appeared to be useful. The first portion of the CST meeting typically did not involve the youth. This first portion might be termed the Professional Planning Meeting. If used, the second portion of the meeting included the youth. This two-tiered process was useful if at least one of the following issues was likely to come up:

- 1. Pathology It was felt that children should not hear excessive discussion as to their own or their families' attributed pathologies. Sometimes, for inescapable reasons, this kind of pathology focus did occur during some CST meetings.
- 2. Money It was also felt that children should not hear excessive talk regarding what their services were worth. This kind of talk was too easily misinterpreted by a youth to mean "What am I worth?"
- 3. Divisiveness It was believed that children should not hear extensive, sometimes even bitter, debate among CST team members regarding what's in the child's best interest. This appeared to be particularly true regarding children who experienced certain types of problem behaviors (e.g., borderline personalities or manipulation). If differences were to be expressed, this expression commonly needed to be done deliberately and in an organized and calm manner after every effort had been made to establish CST group consensus. Whenever possible, CSTs tried to face the child and the service system with a united voice.
- 4. Lack of Candor Sometimes the presence of the child dissuaded certain CST members from engaging in necessary, very frank discussions regarding the exact nature of the child's situation and difficulties. If extremely sensitive issues need to be brought out in the open, the Professional Planning Meeting segment offered a forum for such.



#### Writing the Individualized Service Plan

Preparing the Document. While the content of the ISP was developed by the CST, it remained the responsibility of the coordinator to write and submit the ISP along with an associated Individualized Budget to the State IDT. ISP development was a critical task because it was here that much of the ethic of AYI either was, or was not, represented. If well written, the ISP provided case-specific mechanisms to produce unconditional care, client-centered services, use of the least restrictive alternatives, and trained child helpers. However, several challenges were imbedded in this task. The ISP had to reflect the spirit and letter of the CST's consensus. The multidisciplinary origins of the ISP had to be real, and not just apparent. The ISP had to be holistic, covering the range of the youth's needs. The ISP needed to present relatively detailed action steps with the several CST participants being held accountable for completion of these steps within designated time frames. ISPs needed to be written so that concrete budgetary decisions could be easily and directly derived from these plans. Finally, the coordinator had the responsibility to obtain sign-offs regarding the ISP from each CST member prior to ISP submission to the IDT (also see Flexible Funding section re: Use of Component System).

#### Funding the Plan

Preparing the Individualized Budget. Highly tailored, individualized services are largely possible only with the availability of flexible (highly discretionary) funds (Torrey, 1990). Thus, those local coordinatorships which were in the best position to provide effective wraparound care were those most able to request, manage, and spend discretionary funds. Some of these skills necessarily resided with the coordinator, while others rested with the fiscal personnel of the resident agency. An important coordinator function was to translate ISPs into detailed, defensible Individualized Budgets. The procedures by which this translation occurred evolved slowly. The fiscal procedures described in this section were not substantially articulated until about the end of Year 4.

Once the ISP was written, the Local Coordinator derived a youth-specific Individualized Budget. As discussed in the Flexible Funding section, each IB consisted of three parts (C1, C2, and C3), only one of which (C3) was derived directly from the ISP. The coordinator had responsibility to ensure that all C3 line item costs were related to the ISP's action steps in a direct, point-to-point correspondence. The coordinator also had the responsibility of brokering as many of the ISP-identified service needs as possible, thus minimizing expenses incurred by the flexible funding pool. However, once this brokering function was complete, there still existed an array



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of costs which could not be covered by the categorical funding streams. These costs thus comprised the request for C3 funds (see Flexible Funding section).

Submitting the Budget Request. Submission-of-budget request involved sending the detailed IB and the associated ISP to the State IDT for signature. At this juncture, the IDT's inspection process was largely focused on the appropriateness of the plan and budget and on the ways in which the two were related, issues regarding availability of resources having already been resolved at the time of Coordinatorship Assignment. Within broad limits, there was no programmatic cap on either the nature or the amount of what was an allowable expense. Upon receipt of IDT approval, the coordinator's agency was then able to submit a routine grant amendment.

# Operation of AYI: Service to Discharge

#### Service Initiation

Design and Creation of Individualized Care. The greater the disability and/or disturbance experienced by a youth, the more necessary the individualized services were (Sewell, 1988). This was particularly true in rural and remote areas where very few component services existed. Via the CST-ISP-IB process, Local Coordinators had both the responsibility and the resources to help design and create varied, highly unique services and opportunities around a youth within his or her respective community of tie. As with other coordinator functions, workers varied considerably in their abilities to envision and actually produce highly tailored, previously nonexistent service options on a case-by-case basis. It is difficult to summarize what accounted for service creativity in the individual coordinator. Available funding and the force of circumstance were certainly two important factors. Other factors appeared to include the organizational context within which the coordinator found himself or herself. Leadership, the ability to assume and manage risk, the readiness of the agency to encumber and spend funds to meet highly idiosyncratic needs, and the ability to quickly dispatch staff on a casespecific basis all figured in to a coordinator's ability to create individualized service options. Other variables also figured in such as the flexibility of workers' schedules and lifestyles, as well as previous training and experience in tailoring services. likelihood that the coordinator would create new service options could also be unduly influenced by the extent to which he or she was ideologically attached to and supported by existing component services. Overall, this function probably was one of the most critical to successful casework by the coordinators.

Use of Case-Specific Workers. One critical determinant of a coordinator's success was the ability to identify, recruit, develop, and retain effective child helpers or Individualized Assistance Persons. Many factors played into this ability to find and retain appropriate staff such as personal relationships, knowledge regarding vendors from which to recruit, an ability to quickly create contracts or employee positions, and a capacity to provide ongoing support and consultation to workers in highly idiosyncratic roles.

Provision of Direct Service. Because of time constraints, emergencies, and/or the nonexistence of other resources, local coordinators sometimes provided direct services themselves. While performance of this function did not comprise a large percentage of the coordinator's time, it remained a required part of his or her role.



There were several benefits to this requirement. One was the inherent contingency that if the coordinator planned proactively and well, then the number of emergencies which demanded coordinator involvement was minimized. A second benefit was that coordinators tended to feel an increased sense of personal responsibility and ownership which translated into an enhanced tendency to "do whatever it took" to maintain the youth within his or her community of tie.

### Updating ISPs and Budgets

It was in the nature of the AYI population that service needs changed quickly. There were several reasons for this. AYI youth demonstrated multiple needs, the presentations of which often changed as the youth moved from one placement or service to another. The impact of service (positive or otherwise), exposure to other highly troubled youth, action of maturational and/or pathological processes, change of custodial or legal status, and repercussion of substance abuse were among the numerous influences which could quickly and radically change the youth's range of service needs. AYI coordinators and CSTs needed to be able to detect and respond to these changes in a quick, and sometimes intensive, manner. This meant that it had to be possible for the CST process to be quickly invoked and that changes in the agreed-to service plan also had to be swiftly recorded and submitted. Once the youth's ISP was rewritten, the associated Individualized Budget also needed to be quickly reconfigured and submitted. In addition, coordinators and CST members needed to have the humility to recognize that the first ISP created would not necessarily be the correct match for the youth's special service requirements. Financially, organizationally, ideologically, CST members needed to retain enough flexibility to configure and reconfigure the youth's ISP and related budget as new challenges arose. Critical here was the ability to fluidly provide new staffing patterns as circumstances warranted, particularly during periods of crisis.

In part for these reasons, AYI required that CSTs be reconvened at least every 90 days for the purpose of updating the group's understanding of a youth's recent history, current goals, service options, and anticipated development. This was called the Scheduled Quarterly Review. Emergency and ad hoc CST meetings also occurred often. If the CST case review substantially changed a youth's ISP, then the coordinator was expected to modify the associated Individualized Budget in accord with this. As a group, line workers understood well the changing nature of the troubled youth they served. Thus, they also readily understood that as needs changed, plans and individualized resourcing also had to change. Local and state administrators, however, were far less prepared to adjust to the need for frequent change in youth-specified budgets. Perhaps this was due to the long-established tradition throughout human



services of the categorical funding of component care. As a result, the movement of funds was commonly slow and awkward. This problem underlined the fact that vendors which were larger, and financially more secure were in the best position to tolerate the wait for funds. Ironically, these vendorships were also the ones that could prove to be the most intransigent – this quality seeming to be more true for public than private, non-profit vendors.

### Advocacy and Education

Advocacy for the Rights and Needs of Individual Youth. Early on, it became apparent that the Local Coordinator would have to continually advocate for the best, least restrictive interests and sometimes for the stated wishes of given AYI youth. Workers in the service system see themselves as advocates for a youth's best interest. However, vendor-originated advocacy is easily polluted by the often greater interests of the providing agency. Convenience of staff, reduction of expense, minimization of risk, political expediency, and other factors commonly figure in to what a service vendorship will say and do on behalf of a youth's best interest. To compound this, AYI youth tended to be some of the most difficult-to-serve, dangerous, expensive, tough-to-befriend, irritating, rootless, and/or complex youth in the system. In short, these were the youth who were very likely to be excluded from the vendorship, community, facility, region, and/or even the state. As such, it was necessary that youth-specific, and sometimes ardent, advocacy remain the personal responsibility of each Local Coordinator. This remained true even though the coordinator's interagency role and status could be easily weakened as a result of engaging in such advocacy, which sometimes is the status quo of service delivery. If AYI was to accomplish its primary mission, this function was inescapable, and was necessarily pursued in varied arenas including case conferences, staffings, and, when necessary, court.

Dissemination of Information. Individualized care involved enough new procedures, practices, and beliefs that the Local Coordinators frequently were obliged to perform educational and dissemination functions. This necessitated ongoing training and consultation at varied levels, including in individual homes, schools and agencies, as well as in local interagency and state-level groups.

### Monitoring

Monitoring Behavior of Youth. Several attempts were made to implement a daily behavioral measurement system (Born, VanDenBerg, & Risley, 1988). While well conceived and viable in selected cases, a systematic behavioral measurement system never achieved program-wide circulation. There were several reasons for this,



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important among these was the fact that data collection technology was neither robust enough nor straightforward enough to be of use across the extreme variety of settings and workers which comprised AYI. This behavioral assessment effort has continued to successfully evolve in Vermont's Daily Adjustment Indicator Checklist (DAIC) (Burchard & Schaefer, 1990).

Monitoring Service Delivery. To hold workers in other organizations accountable is a delicate matter. To examine a particular youth's behavior is one issue, but to examine the behavior of relevant system workers with respect to that child involves a remarkably different technology and politic. A good deal of ongoing vendor assessment was accomplished through relatively informal channels such as phone calls or brief meetings. Perhaps the most systematic attempt at vendor (and youth) monitoring was an effort which became known as Proactive Client Tracking (Sewell, 1990d).

Proactive Client Tracking (PCT) was an attempt to systematically address varied case monitoring, support, and coordination needs regarding AYI youth in various Essentially, PCT was carried out by paraprofessional workers who made weekly telephone contacts with critical adults (from one to five) in each youth's life. Discussion centered on the current status of the youth, as well as on the personal, social, and service context within which the youth lived. Questions were raised regarding both overall well-being and client-specific issues related to each of the eight major Life Domains identified in Chapter 1 of this document. The contacted key informants variously were relatives, childhelpers, teachers, clinicians, child protection workers, probation officers, and/or other key decisionmakers within the child's life who had at least weekly, and preferably daily, contact with the youth. Extensive notes were kept which reflected the plan's required holistic emphasis. This and other information was summarized into a weekly report and submitted both to the Local Coordinator and to selected state-level IDT members. Structured this way, PCT was a useful aid for the case coordinator trying to make informed, timely ISP decisions for a caseload of youth who displayed severely maladjusted behaviors and who were scattered over a large expanse.

Monitoring Individualized Budgets. In the end, budget monitoring remained the personal responsibility of the coordinator, but the coordinator's home agency could either markedly facilitate or impede that effort. Depending upon which organization served as the coordinator's home office (and thus, as fiscal agent for the youth's ISP), the coordinator could face major obstacles to ensuring that the flexible funds were spent in a timely manner and only upon those line items which had been specified in the youth's ISP.

### Discharge

How youth were discharged from AYI and, indeed, even what that process was called, became a source of ongoing discussion and debate. At issue were things such as the meaning of unconditional care, acceptable evidence of effective service, the circumstances under which funding increments and reductions would occur, how success rates and current caseloads per worker were calculated, what constituted the best use of priority funds, and how to best address the concerns of varied advocates and other stakeholders. As long as the option of discharge remained at the local level, little progress was made concerning these issues. However, during Year 5, the IDT formally consolidated the discharge process and became the recognized body by which services were brought to a close for a given AYI youth (Alaska Youth Initiative's Interdepartmental Team, 1991). Discharge petitions became a part of the IDT hearing process, along with opportunity for redress.

Careful, youth-specific planning for transition out of AYI was often an important determinant of post-AYI success. As part of this planning, key stakeholders needed to be advised early on in the process that a youth was going to be transitioning out. In part, this helped to reduce some of the emotionality which occasionally attended service reduction. However, by the end of Year 5, there still remained marked discontinuity between AYI and an adult Severely Mentally Ill service system on the one hand, and the component child and adolescent service system on the other.

## Conclusion

Over the course of 5 years, AYI was able to bring to a virtual halt Alaska's former practice of placing youth in restrictive, out-of-state facilities. In the process of accomplishing this mission, AYI was also able to evolve several useful practices which have become collectively known as individualized services. As was suggested throughout this section, there are several reasons for excitement regarding these developments. One is that many of the AYI youth have been provided lifestyles in the community which were thought not possible as little as a decade ago. Beyond the successes of the particular youth in the initial cohort, there are several system reasons to be excited. For one, it appears that some of AYI's service, administrative, and fiscal strategies may be of use in other varied settings and with other varied populations. To an extent, both Alaska's developmental disabilities and SMI service communities have adapted certain elements of the individualized services approach to their own efforts. In addition, numerous other states and counties around the United States have begun intensive individualized service efforts for their own youth with severe emotional What the future holds remains a matter of conjecture for both individualized care in general, and for AYI in particular. It is the belief, however, that if AYI continues to develop to the point that it has served its 500th youth, it will have truly and substantially changed Alaska's SED system "one kid at a time."

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